A narrative inquiry of socio-cultural influences on Antiretroviral treatment and medication experiences of African-born persons living with HIV in Minnesota

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Introduction

History

In the early 1980s the landscape of infectious diseases changed dramatically by the identification of a mysterious disease later termed human immunodeficiency virus (HIV). Initially, scientists around the globe were intrigued and challenged by a new disease that did not appear to resemble the characteristics of any other.

The scientific world was confronted by numerous cases reported globally. For example, according to Timberg and Halperin, European physicians were reporting deaths due to this new disease in Copenhagen, Paris, and Seville. These deaths were most prevalent in the homosexual community and among hemophiliacs. However, the situation in Belgium was apparently different. Belgium physicians were finding cases of the new diseases in wealthy Africans who had travelled from African colonies (Timberg & Halperin, 2012). At the same time, the very first cases of an unusual pneumonia due to an organism named *Pneumocystis carinii* were reported in Los Angeles (Timberg & Halperin, 2012). On the other side of the U.S., New York physicians were confronted with new cases of Kaposi Sarcoma (France, 2016) which was one of the manifestations of this new disease (Shilts, 1987). Meanwhile, the first case was reported in Latin America, more precisely in Brazil (France, 2016). Africa had previously seen many deaths from this mysterious disease; where it had been named the “slim disease”

(Iliffe, 2005; Timberg & Halperin, 2012). However, at this early stage the scientists and the medical staff were not aware of the fact that a future pandemic was imminent.

In the U.S., the new disease occurred more predominantly in the gay community and it was named for a short period of time as the “gay-related immune deficiency” or “GRID” (France, 2016). The terminology changed from GRID to HIV (human immunodeficiency virus) in the early 1980’s when Western medicine identified HIV in other populations including women, hemophiliacs, and children (Shilts, 1987; J. H. Smith & Whiteside, 2010).

The first U.S. case of HIV was documented on May 11, 1982 in an article published in the *New York Times* (Markel, 2001). However, a year earlier, the *Morbidity and Mortality Weekly Report* bulletin from the Center for Disease Control (CDC) had described an usual type of pneumonia in homosexual men from Los Angeles (Shilts, 1987; Timberg & Halperin, 2012).

The controversy relating to the origins of HIV continues today. According to Timberg and Halperin, HIV originated in the early 1900s in Cameroon (Timberg & Halperin, 2012). However, there is limited evidence to confirm or deny these findings. These authors discuss the presence of some rare cases of HIV in the early 1950s and 1960s in both Cameroon and Congo (Timberg & Halperin, 2012). The virus spread from Cameroon to Leopoldville, Congo later continuing its journey to other parts of Africa.

The question arises of how HIV spread from Africa to the U.S. and when. Timberg and Halperin (2012) provide a plausible explanation in their book. They discuss the appearance of HIV cases in the U.S. initially in Florida (Timberg & Halperin, 2012). According to Timberg and Halperin, Florida physicians noticed unusual cases of tuberculosis (TB) with enlarged lymph nodes in Haitian immigrants in 1979 (Timberg & Halperin, 2012). The enlarged lymph nodes are observed symptoms in HIV cases, while TB is commonly detected in people with weak immune systems such as HIV.

At this stage another question was raised: how did the Haitians get infected with HIV? According to the authors, during the political and economic Congo crisis in the middle of the 1960s, the Congo government brought educated and skilled workers from Haiti to Congo to work because the Haitians and Congolese spoke French. (Timberg & Halperin, 2012). The Haitians received good remuneration which allowed them to fly back to Haiti for vacation and to visit their families (Timberg & Halperin, 2012). It has been proposed that the virus was passed to family members and others during these vacations to Haiti (Timberg & Halperin, 2012).

To conclude, the process of HIV journey through the U.S. and the rest of the world is best described in the following paragraph. A medical doctor in Florida who treated Haitian patients was able to save the specimens of the blood that showed the virus journeyed “from Kinshasa to Haiti, then onward to Miami, New York, San Francisco, London, Paris. Nearly every person to get AIDS in the

Americas and Europe contracted a descendant of the virus that made this original trans-Atlantic hop sometime during the 1960s." (Timberg & Halperin, 2012, p. 72)

The book "And the Band Played on" which describes how the medical world disputed the initial identification of the virus responsible for the condition described as HIV/AIDS (Shilts, 1987). According to Shilts (1987) two teams of scientists were working concurrently in the identification of the virus. One team was from Pasteur Institute in France and the other one from National Cancer Institute (NCI) who were collaborating at the time with Dr. Robert Gallo (Shilts, 1987). According to the historians, the credit was given to the team from the Pasteur Institute wherein 1983 the virus was identified (Hillman, 2016; Shilts, 1987). For this significant discovery, the French team received the Nobel Prize for Medicine in 2008 (Hillman, 2016).

In the following years, the scientists around the globe identified two forms of HIV viruses: HIV-1 and HIV-2 (Iliffe, 2005). Each form of the virus has different geographic confinement and virulence (Iliffe, 2005). For example, HIV-1 is spread globally, while HIV-2 is restricted to the West Africa coast and is less virulent (Iliffe, 2005). It was determined that both forms of HIV were the main causes of Acquired Immune Deficiency Syndrome (AIDS) (J. H. Smith & Whiteside, 2010).

HIV in Africa

Initially in the early stages of the pandemic, the African reports did not receive much attention. It took nearly a decade for scientists and clinical staff to recognize the pandemic on the African continent (J. H. Smith & Whiteside, 2010).

The recognition resulted in different resources being made available to Africa. Specifically, the birthplace of the United Nations AIDS (UNAIDS) in 1996 lead to the development of programs and data collection.

Different countries in Africa have been affected differently by the HIV pandemic; some countries have a higher rate of HIV infections than others. For example, in the early 1990s in countries that belonged to the “AIDS belt,” nearly 25 % of the people living in the cities were suffering from HIV (Caldwell & Caldwell, 1996). The following countries belonged to the “AIDS belt”: “Central African Republic, Southern Sudan, Uganda, Kenya, Rwanda, Burundi, Malawi, Zimbabwe, Tanzania, Zambia, and Botswana” (Caldwell & Caldwell, 1996 p.15-16). These high rates of HIV infection in the “AIDS belt” were attributed to the absence of male circumcision (Caldwell & Caldwell, 1996 p.18). On the other hand, Nigeria’s population had an HIV infection rate of 0.5% (Caldwell & Caldwell, 1996).

The World Health Organization (WHO) estimated that around 36.9 million people were living with HIV globally in 2017 (WHO, 2018). Africa has the highest prevalence of HIV where approximatively 25.7 million people are infected (WHO, 2018). Furthermore, out of 1.8 million global new infections, 1.2 million occurred in Africa (WHO, 2018).

Statistics in the U.S. and Minnesota

According to the Center for Disease Control and Prevention (CDC), there are more than 1.1 million people living with HIV (PLWH) in the U.S ("CDC Basic Statistics," 2017). In 2015 an estimated 38,500 persons were newly infected with

the virus ("CDC Basic Statistics," 2017). However, one out of seven were not aware of their infection ("CDC Basic Statistics," 2017). In 2016, 39,782 persons received the diagnosis ("CDC Basic Statistics," 2017). The diagnoses have had a disproportionate effect on different minorities such as African-Americans. For instance, most of the HIV diagnoses occurred in the southern states. In 2016, 44% of the new virus diagnoses were in African-Americans who represent 12% of the U.S. population ("CDC Basic Statistics," 2017). In the CDC reports present the statistics for African Americans; however, the reports do not separate between African-born and African Americans. Therefore, there is no nationwide statistics to distinguish on the number of African-born persons living with HIV in the U.S.

In the last three decades, Minnesota has seen an increase in the number of immigrants from Africa, noticeably in the mid-1990s. In the last report from the Minnesota Department of Health (MDH), some community members estimate that number to be close to 100,000 African immigrants that represents approximatively 2% of the total Minnesota population (Minnesota Department of Health, 2018).

Current data shows a steady rise in the newly HIV infections among African-born PLWH in Minnesota in the last decades (Minnesota Department of Health, 2018). To illustrate, there were eight new HIV infections in 1990, which in 2002 increased to 65 new HIV infections ("Minnesota Department of Health,"). Out of the 284 new confirmed cases of HIV in 2017, 60 occurred in the African-born population (Minnesota Department of Health, 2018). Furthermore, the recent report showed that the African-born population has the highest incidence rate of

55.6 (per 100,000) compared to other racial groups with rates of 2.2 for Caucasians and 46.6 for African-American (MDH, 2017).

While the African-born population is approximately 2% of the total population of Minnesota, 21% of new HIV infections in 2017 occurred in this population mostly from the Twin Cities metropolitan and surrounding area (Minnesota Department of Health, 2018).

Risk Factors

Globally, the majority of HIV infections occur through heterosexual unprotected sexual contact with an HIV positive person (Laga et al., 1993). Infected females could transmit the virus to a newborn during pregnancy, delivery, and breastfeeding (Shannon et al., 2008). Sharing contaminated needles or injections represent another risk factor for transmission of the virus. The virus could spread in Men who have Sex with Men (MSM) through unprotected sexual contact with an infected partner (Strathdee et al., 2001).

The virus is not spread through casual contact that includes using swimming pools, food utensils, bedding, and toilet seats ("CDC Basic Statistics," 2017).

Treatment

The first hope for HIV treatment occurred in 1987 when the experimental drug zidovudine also known as AZT was launched to the market (Cimons, 1987). In the following years, other medications for the treatment of HIV received approval for human use. For example, in 1995 there were only five antiretrovirals available

to treat PLWH, while in 2000 the market saw a sharp increase to nearly 16 medications (Henry, 2000). Furthermore, in 2018 there are at least 40 ARV medications on the U.S. market from five different classes to select for treatment (FDA, 2018, April 12). One of the main advantages of the newer medications is that they are less toxic and more tolerable than the initial ones (Saag et al., 2018).

The development of ARV medications for HIV over the last two decades has transformed treatment for HIV from an acute, palliative focus to a long-term, managed effort. According to the current guidelines, all HIV positive persons should be started on ARV regimen regardless of their CD4 counts (NIH, 2018). The rationale for this recommendation is to decrease mortality and morbidity associated with HIV infection (NIH, 2018). Commonly, an initial ARV regimen consists of three ARV medications that belong to at least two different classes (NIH, 2018).

The importance of adherence was described by various authors (Edwards, 2006; Wong & Ussher, 2008). In the case of patients taking ARV medications, they should take 95% of the prescribed doses to obtain viral suppression and avoid resistance development (Paterson et al., 2000). Sustaining adherence to the ARV medications and achieving viral load suppression decreases the chances of virus transmission over time and reduces the risk of infection. In other words, an undetectable HIV viral load translates into persons living with HIV (PLWH) becoming untransmittable (CDC, 2017). In October 2017, the CDC released a letter in which it endorsed a public statement, “U=U” or “Undetectable Equals

Untransmittable” (CDC, 2017). The CDC endorsed the “U=U” statement based on three landmark studies. Furthermore, in October 2017 the Minnesota Department of Health also launched this “U=U” campaign. The main goal of this “U=U” campaign was to inform everyone about the importance of taking ARV medications ("State health agency joins effort to limit HIV transmission and reduce stigma," 2017). Ultimately, adherence to ARV medication also decreases the risk of drug resistance, improves quality of life and ultimately increases life expectancy (Mocroft et al., 2013; Paterson et al., 2000).

Key to this present study is to explore factors which promote or inhibit adherence to ARV in African-born population. According to the World Health Organization (WHO), adherence has been defined as “the extent to which a person’s behavior– taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed upon recommendations from a health care provider” (WHO, 2010). Medication compliance, on the other hand, refers to the act of conforming to the recommendations made by the provider with respect to timing, dosage, and frequency of medication taking. “Compliance” and “adherence” are two terms sometimes used interchangeably in the literature. Therefore, medication compliance may be defined as “the extent to which a patient acts in accordance with the prescribed interval and dose of a dosing regimen” (Bailey et al., 2015). Therefore, this thesis will use the term “adherence” to avoid any confusion (Bailey et al., 2015; Hugtenburg, Timmers, Elders, Vervloet, & van Dijk, 2013).

Literature Review

A literature review revealed three quantitative studies conducted in the US. These three studies were retrospective chart reviews of HIV-positive African-born patients who received ARV therapy in the US (Akinsete et al., 2007; Blood, Beckwith, Bazerman, Cu-Uvin, & Mitty, 2009; Winston et al., 2013). Below is a summary of these three core studies.

Study 1 ("Demographic, Clinical, and Virologic Characteristics of African-Born Persons with HIV/AIDS in a Minnesota Hospital")

Study 1 conducted in Minnesota provides some information on the demographics of the population of interest. The study investigated the "HIV-1 genotyping and subtyping" infection in HIV-positive African-born patients (Akinsete et al., 2007, p. 207). The Hennepin County Medical Center (HCMC) database was reviewed by two independent investigators (Akinsete et al., 2007). The clinical outcomes assessed were CD4 counts and viral load (Akinsete et al., 2007). These outcomes of interest were compared to those of non-African participants (Akinsete et al., 2007). Study's participants were above age 18, African-born, HIV-positive, and enrolled as patients in the clinic at Hennepin County Medical Center (HCMC) between January 1994 and June 2005 (Akinsete et al., 2007). This study identified 237 patients who were from different geographic areas of Africa, "representing 23 different countries" (Akinsete et al., 2007, p. 358). Most of the participants in this study were immigrants to the U.S. and not refugees (Akinsete et al., 2007).

The findings from this study showed that 55% of all African-born patients were on ARV regimens when data collection occurred (Akinsete et al., 2007). Most of these participants started receiving ARV treatment in the U.S. Additionally, this study reported one case of transmission of HIV from mother to fetus because the mother rejected to take ARV treatment (Akinsete et al., 2007).

Study 2 ("Evaluation of Longitudinal Clinical Outcomes and Adherence to Care among HIV-Infected Refugees")

The second study was conducted on HIV-positive patients who were African refugees living in Rhode Island. The study reviewed 51 patients' charts between 2000 and 2008 (Winston et al., 2013). This study assessed the adherence to clinic appointments in addition to CD4 counts, viral loads, and opportunistic infections (Winston et al., 2013). This study focused on circumstances and barriers to adherence encountered by African HIV-positive refugees in the US (Winston et al., 2013). The study evaluated CD4 counts, viral loads, antiretroviral treatment use, appointment adherence, opportunistic infections, and resistance mutations (Winston et al., 2013). The medical charts of "51 HIV-infected sub-Saharan African refugees were matched with the charts of 102 non-refugees" as referred by the study (Winston et al., 2013, p. 202). In the study, one refugee was matched with two non-refugees "by gender, CD4 category (<200, 200-350, and >350 copies/mL), and closest date of their initial appointment using an optimal variable matching algorithm" (Winston et al., 2013, p. 203).

Refugees did not differ from non-refugees in the appointment adherence in the first year of study (Winston et al., 2013). However, the refugees differed in appointment adherence after the third year and later (Winston et al., 2013). The reasons for evaluating the appointment adherence beyond three years were not mentioned by the authors (Winston et al., 2013).

Most of the refugees did not differ from non-refugees in achieving viral load suppression (Winston et al., 2013). However, the study found that five non-refugees and three refugees did not achieve the viral load suppression (Winston et al., 2013). Additionally, refugees presented with more inconsistency in viral load following suppression, “having on average some 2.3 higher odds of viremia following an undetectable VL compared to nonrefugees (95% CI 1.18-4.48, P < .05), adjusted for foreign-born status and clinical trial enrollment” (Winston et al., 2013, p. 205).

The study found that the initiation of ARV in non-refugees was earlier than that for refugees (Winston et al., 2013). However, the difference was not statistically significant (Winston et al., 2013). On the other hand, refugees were not as willing as non-refugees to sign up in clinical trials (Winston et al., 2013). Other differences between the refugees and non-refugees were in the presence of opportunistic infections and illegal drug usage (Winston et al., 2013). The most common opportunistic infection was tuberculosis - present in 12% of refugees versus 6% of non-refugees (Winston et al., 2013, p. 204). Additionally, “refugees

were more likely to be diagnosed with latent tuberculosis (20%) than non-refugees (4%)" (Winston et al., 2013, p. 204).

Study 3 ("Pregnancy among HIV-infected refugees in Rhode Island")

The third quantitative study was also conducted in Rhode Island between 2000 and 2008 (Blood, Beckwith, Bazerman, Cu-Uvin, & Mitty, 2009). The study sample was 28 HIV-positive women African refugees (Blood et al., 2009). Most women in this study were from Liberia (Blood et al., 2009). This study also found that there were 20 pregnancies during the period considered (Blood et al., 2009).

Other adherence-related concerns with regards to the female HIV-positive refugees were pregnancy and the potential for transmission of the virus to the child. One of the main goals of Study 3 was to gain a better understanding of the challenges in this population including the commencement of medical care, and comprehensive "preconception counseling"(Blood et al., 2009, p. 208). A retrospective chart review and clinical interviews looked at all HIV-positive women refugee patients who initiated care in Rhode Island from 2000 to 2006 (Blood et al., 2009). The study reviewed 28 HIV-positive women refugees' charts (Blood et al., 2009). Twenty pregnancies were reported during this period (Blood et al., 2009). "The median age at time of first pregnancy was 29 years" (Blood et al., 2009, p. 207).

The study found that most of the female participants were originally from Liberia and most of them (71%) stated they knew ''some'' English (Blood et al.,

2009, p. 208). The study reported that all women received ARV therapy during their pregnancy in accordance with the guidelines (Blood et al., 2009).

Overall, this study found that most refugee women who became pregnant could maintain peak CD4 counts and decreased viral loads (Blood et al., 2009). The authors reported one case of transmission of HIV (Blood et al., 2009). In this case, nonadherence to ARV treatment was speculated to be the main reason for this outcome (Blood et al., 2009). The study reported not knowing the outcome for one patient who relocated to a different address and did not come to the clinic for a follow-up (Blood et al., 2009).

This literature review shows a gap in findings based upon qualitative studies conducted in the US. Additionally, the literature search showed a limited number of qualitative studies conducted globally. For example, three studies conducted in London, United Kingdom, presented the social-economic factors faced by this population in a country with different healthcare settings compared to the U.S. (Erwin & Peters, 1999; Spiers, Smith, Poliquin, Anderson, & Horne, 2016; Thomas, Aggleton, & Anderson, 2010). However, these studies did not discuss the facilitators and barriers to take ARV regimens and the interaction between pharmacists and patients.

Significance of Research

Clearly, this study will add more knowledge to the literature because it will explore the socio-cultural, personal and economic factors in this understudied population and the pharmacists' roles in enhancing adherence.

The benefits of identifying the factors that promote or inhibit adherence to ARV therapy in African-born patients will largely impact PLWH and the public in general. Understanding patients' beliefs and potential economic factors implicated in taking ARV medications will allow the clinical pharmacists to more effectively address patients' needs. Moreover, the patient will be able to sustain daily work activities that will indirectly have an impact on the society's economy. Prior research demonstrates that in the face of barriers to taking the prescribed ARV regimen, PLWH may stop taking their medications. Consequently, such patients are likely to develop HIV strain resistant to the medications. If they infect other people, the resistant virus is transmitted. The impact on the society is much wider in this situation, because these newly infected patients have limited treatment options. The proportion of patients newly infected with a resistant virus has been reported (Wagner & Rabkin, 2000).

Study Aims

The aims of this study are as follows:

(Aim 1): Capture the lived experiences of African-born HIV positive patients' who are taking ARV treatment.

(Aim 2): Reveal the cultural and personal beliefs as well as socio-economic factors about medications of African-born HIV positive patients.

(Aim 3): Understand the influence of these beliefs and impact of economic factors on their decisions to follow ARV treatment.

(Aim 4): Explore patients' perception of clinical pharmacists' roles in fostering adherence to ARV therapy.

Methods

As a research methodology, Narrative Interviews (NI) elicit the story of individuals and have been used in many fields including sociology, psychology, nursing, and pharmacy (Riessman, 2008). In the qualitative literature, the word storytelling is often used for NI. This terminology is substitutable (Riessman, 2008).

A key purpose of NI is to encourage and inspire the participant to share a significant event of his/her life with the interviewer (Muylaert, Sarubbi Jr, Gallo, Neto, & Reis, 2014; Riessman, 2008). One of the functions of storytelling is to have the audience participating in the experience of the narrator. In other words, the narratives invite all the participants, including listeners, readers, and viewers to enter the perception of the narrator (Riessman, 2008).

One of the main characteristics of NI is the use of semi-structured dialogue with probing questions if the participant does not discuss the topic in the probes (Muylaert et al., 2014; Riessman, 2008). The interviewer impact in the narrative process should be negligible because the purpose of NI is to allow the interviewee to freely recreate social events (Muylaert et al., 2014).

A significant advantage of using NI is to elicit emotions in the audience members (Muylaert et al., 2014). The provoking of emotions allows both the interviewer and the reader to integrate the interviewee's narrative with their own experiences, sidestepping judgements and being open to different interpretations. In this instance, the prospect of narrating and passing the story to another person

facilitates “the experience that is finite, infinite, and of fundamental importance for the construction of the collective notion” (Muylaert et al., 2014, p. 185). During NI it is important to elicit the story as it happened presenting the times (past, present and future). Then while writing their stories, the interviewer should articulate the past in the form of narrated experiences and without any interpretation (Polkinghorne, 1988) .

Participants and Settings

Sample Size

To determine the sample size in qualitative research, the researcher does not use software or statistical power as in quantitative research (Morse, 1991). Morse (1991) suggests a target sample size of 10 participants for NI studies. Additionally, qualitative researchers look for thick descriptions and rich themes that emerge from the interviews as a way of determining the sample size in this study (Geertz, 1973).

Data Collection

The study participants were fourteen African-born persons living with HIV currently taking ARV medications and reside in Minnesota. Participants were recruited using purposive selection methods. Participants were recruited through fliers placed in pharmacies such as Walgreens and the HIV Center located in the

Twin Cities area of Minnesota (See Appendix # 1). The fliers had the researcher's contact information and an explanation of the research study. Interested persons were required to contact the student principal investigator (SPI) by phone and set up convenient interview times.

Inclusion criteria:

- African-born 18 years old and over, Minnesota residents
- Diagnosed with HIV
- Currently taking ARV treatment
- Willing to share their experiences of being HIV positive and ARV treatment.

Exclusion criteria:

- Non-English speaking
- Minors (less than 18 years old)
- Individuals who are HIV positive but have never been prescribed ARV treatment.

During the interview, each participant received a pseudonym such as “Participant # and Gender” for confidentiality reasons.

At the beginning of each interview, the purpose of the study was explained, questions were answered, and an informed-consent form was reviewed by the participant (Appendix # 2). The SPI asked for permission to audio-record the interview. All the participants consented to having the interview audio recorded. All the interviews were one-on-one, with length ranging from half an hour up to two hours. Each of the participants was offered compensation (a $50 gift card) for their

participation in the study, to minimize inconvenience and reimburse them for their time and associated costs of participation (e.g., childcare, transportation).

Recruitment for the study started in December 2017 and continued until thick and rich descriptions were achieved in April 2018.

The NI questions were developed by the SPI based on extensive review of literature. To ensure that the instrument aligned with the scope of this research, the PI consulted with her team comprised of experienced researchers and health professionals (pharmacists and physicians) specializing in HIV. The NI questions were divided into three sections that resonated with the aims.

The first section included questions related to African-born HIV positive patients' experience on taking ARV medications. The second section was designed to collect information about the patient's cultural and personal beliefs as well as socio-economic factors that might influence their decision to take ARV medications. The third section was designed to collect information on the patients' perceptions of pharmacists' roles in fostering adherence to ARV regimens. For the instrument with probes/follow-up questions, please see Appendix # 3.

Some of the NI questions were adapted from those used in several qualitative studies. The NI questions were reviewed for content and clarity by one specialized (Board Certified) pharmacist in the field of HIV/AIDS. In the fall of 2017, a pilot interview was conducted with an African-born individual who was not HIV positive. The interview was not audio recorded. Additionally, the questions were pilot-tested on three persons who are African-born, but for whom English was a

second language. The objectives of the interview and pilot-testing of the questions were to refine these and to ensure clarity and comprehensibility.

Ethical Considerations

Approval of this study was received from the Institutional Review Board (IRB) of the University of Minnesota IRB (See Appendix # 4). Informed consent was obtained from each participant prior the interview. To ensure anonymity, participants were not required to provide their name or asked to sign the informed consent form. To assure the study participants of their confidentiality and anonymity, the venue and the time of the interview remained undisclosed. Any names mentioned unintentionally during the interview, were deleted from the transcripts. The digital files and the transcripts were stored in a password-encrypted file on the SPI's computer where only the SPI and PI had access.

Data analysis

The data analysis followed the following steps:

1) Transcription and Memos

The initial step before data analysis is transcription. After the interviews were audio recorded, the records were transcribed verbatim by a professional transcription service (QHR Consultants, Madison, WI). Then the SPI read over the transcripts multiple times to immerse herself in the world of the participants. While reading the transcripts, the SPI took notes in the form of reflective memos (Birks,

Chapman, & Francis, 2008). Memos caused the researchers to be involved with their research to a greater degree (Birks et al., 2008).

Qualitative research uses three types of memos: personal, method, and analytic. The memos were described by Rubin & Rubin as “reformulations of the research question” (Rubin & Rubin, 2011, p. 191). In other words, the role of memos is to bring clarification about the research question (Birks et al., 2008). Another key characteristic of the memos is to enable the SPI to comment on the feelings felt during the interview, or if biases were detected (Birks et al., 2008; Rubin & Rubin, 2011). In a similar vein, memos have been described by Birks *et al.* as “the vehicles that transport the researcher from the concrete to the conceptual” (Birks et al., 2008, p. 71).

Before analysis took place, the SPI took time to reflect on the preconceptions she had about the experience of the population of interest as part of her personal memo. This personal memo was expanded as the research proceeded and used to ensure that these preconceptions did not influence the analysis and interpretation of the.

In analytic memos, the investigator uses different analytical approaches that facilitate the abstraction of the meaning from the data that will be articulated in conceptual terms (Birks et al., 2008). This is an important step in data analysis because memos allow the occurrence of the conceptual terminology. Memoing assists the researcher in resolving the issue “What is actually happening in the data?” (Birks et al., 2008, p. 70). Furthermore, memoing enables the investigator

“to articulate, explore, contemplate an challenge their interpretations when examining data” (Birks et al., 2008, p. 71). To sustain a good communication and uniformity between the data and the investigator, analytic memos are an important approach (Birks et al., 2008). The purpose of writing analytic memos is to explain the connections between the codes and categories (Miles, Huberman, & Saldana, 2013).Furthermore, the primary aim of writing the analytical memos at this stage is conceptual (Miles et al., 2013). Thus, the analytic memos play an important role because they bind together the various fragments of data into a well-established entity called category and theme (Miles et al., 2013).

2) Summary, Notable Quotes, Coding and Development of Themes

After each interview took place a “summary of the contents” was written (Rubin & Rubin, 2011, p. 192). The summary included primarily “the points expressed by the participant, pseudonym of the participant, the time, location, and the duration of the interview” (Rubin & Rubin, 2011, p. 192). The summary points out “important perceptions the interviewer” (Rubin & Rubin, 2011, p. 196).

While reading and coding the interview, whenever quotes are representatives, or stand out, they were marked as notable quotes. Almost each primary code had a few notable quotes. It is important to mark the notable quotes because they could reveal themes that might answer the research question (Miles et al., 2013).

The role of qualitative analysis was described by Hsieh and Shannon as “a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns”

(Hsieh & Shannon, 2005, p. 1278). To illustrate, Hsieh and Shannon described three approaches for analysis: a) Conventional b) Directed c) Summative (Hsieh & Shannon, 2005).

Conventional Content Analysis was selected as the main method for NI analysis (Hsieh & Shannon, 2005). Whenever “a phenomenon, or emotional reactions experienced” by the participants have to be explained then Conventional Content Analysis should be used for data analysis (Hsieh & Shannon, 2005, p. 1279). Furthermore, if there is not enough research information on a phenomenon, the researcher should use Conventional Content Analysis (Hsieh & Shannon, 2005). A key characteristic of the Conventional Analysis is not using preconceived categories. On the contrary, the Conventional Content Analysis enables the categories and names for categories to arise from the data (Hsieh & Shannon, 2005). In this situation, researchers engage themselves in the data that foster new perceptions (Hsieh & Shannon, 2005). This method has been described in the qualitative analysis as inductive category development (Hsieh & Shannon, 2005).

During the initial step in the inductive coding process, the participant “exact words” that depict important concepts must be selected for each line or paragraph (Hsieh & Shannon, 2005, p. 1279). This process enables the labels for codes to arise. Usually, these codes are representative insights of the main ideas and are taken straight from the interview (Hsieh & Shannon, 2005). Coding has been defined as a “deep reflection” and “deep analysis and interpretation of the data’s meanings” (Miles et al., 2013, p. 72). A key characteristic of codes is to obtain a

retrieval of what was said on each topic (Miles et al., 2013). Thus, codes are referred to as “prompts or triggers” for a more profound reflection on the data (Miles et al., 2013, p. 73). Inductive coding will occur line by line and will facilitate the development of initial codes (Miles et al., 2013). Each code will have a descriptor to enable the differences and similarities between codes.

After all the codes were extracted, the codes were analyzed based on similarities (Hsieh & Shannon, 2005; Miles et al., 2013). A vital step while developing categories was writing the descriptors for each code. The similar codes were combined and facilitated the development of categories. After the development of the categories, then two or three categories were linked based on the commonalities of content topic that facilitates the development of themes (Hsieh & Shannon, 2005; Miles et al., 2013). Themes were described by Rubin and Rubin, as “summary statements, causal explanations, or conclusions” (Rubin & Rubin, 2011, p. 194). Themes usually reflect the connection between the categories (Rubin & Rubin, 2011). Furthermore, they provide explanations of an event, or the meaning of a story (Rubin & Rubin, 2011). Analytic memos were written during the analysis process that assisted in the theme’s development.

The above steps were conducted using Dedoose, a qualitative software that enables all the memos, codes, categories, and themes to be kept organized. Furthermore, Dedoose enabled an easy retrieval of codes, themes, and quotes.

Considerations of Rigor

Lincoln and Guba's framework was used to address and meet criteria for quality and rigor (Lincoln & Guba, 1985). These authors recommended four criteria, credibility, dependability, confirmability, and transferability to critique narrative research studies (Lincoln & Guba, 1985).

Credibility attributes to the trust of the corpus of data and its understanding (Lincoln & Guba, 1985). To ensure this criterion is reached, two aspects should be taken into consideration (Lincoln & Guba, 1985). First, the method used to conduct the study must increase the trustworthiness of the results. Second, to ensure credibility is reached several steps are considered (Lincoln & Guba, 1985).

This criterion was achieved by using reflective journaling, memos, audiotaping and verbatim transcription by an independent company, saturation of data, intercoder checks, and development of the codes. In this study, the codes were reviewed by two researchers (JS and OO). For example, one researcher reviewed the codes of two transcripts; while the other researcher (OO) coded independently four interviews. Then, the team met several times to discuss the codes and consensus was achieved. The rationale for reviewing all the codes by two independent researchers was to prevent researcher bias and selective inattention and provide rich quotes from the transcripts in the results chapter.

Dependability indicates the solidity of data over a period and across situations. In other words, credibility cannot be reached without dependability and vice versa (Lincoln & Guba, 1985).

This step was obtained by careful documentation that occurred in the interview process. For example, after each interview, the SPI wrote summaries that captured non-verbal communication that might be relevant to the data analysis. These summaries also included the SPI's thoughts on the interview questions that might have had to be rephrased and areas for further questioning when interviewing other participants. A few of the interviewees mentioned some relevant information after the audio recording was stopped. Therefore, the SPI asked for the interviewee to restate the sentences that could be captured on the audio recording.

Confirmability refers to the possibility of reaching congruence between two or more team members regarding the data's relevance, sense, and accuracy (Lincoln & Guba, 1985). The roots of this criterion are in the information provided by the data that ensures the interpretations of the participants' words are represented accurately (Lincoln & Guba, 1985). A key aspect of this criterion is that the results of the data interpretation must echo the participants' words and not the biases and viewpoints of the investigator (Lincoln & Guba, 1985).

This criterion was accomplished by careful documentation, intercoder checks, and the development of the codes that have been discussed in the previous pages.

Transferability discusses to the level to which the results of the study might be transferred to or have applications in other settings (Lincoln & Guba, 1985).

This step was obtained by thick, vivid explanations. After each interview, the SPI read the data to compare it with the previous interviews to see if additional interviews were necessary. The thick and rich descriptions were achieved at the fourteenth interview, at which point no new information was forthcoming.

Authenticity: For this criteria, the investigator presents the data that is representative of different experiences (Lincoln & Guba, 1985). Thus, the person reading the manuscript can feel the emotions; enabling them to re-live the participants' experiences.

This criterion was obtained by reflective journaling, audiotaping, verbatim transcription, thick, vivid descriptions, and meaningful writing. The rationale for reflective journaling was to clarify the assumptions of the researcher. For example, reflective journaling allowed rigor building because it captured non-verbal responses during interviews and other experiences during data collection.

Results

The goal of this study was to illustrate the African-born HIV positive Minnesotan participants' socio-cultural, and personal beliefs, as well as economic factors and how they influence patient perception of taking the ARV regimen. Specific aims for this study are to describe African-born HIV positive, their stories from the moment of diagnosis, the role played by medications in their lives, and how they navigate the US healthcare system.

The results of this study will be presented in the following two sections. The first section presents the demographics of the 14 participants interviewed. The second section presents the themes extracted from the Conventional Analysis.

Demographics of the participants

A total of 14 participants were interviewed for this study. All participants were taking ARV medications at the time of the interview. To ensure their confidentiality to this study, no names were asked. During the interview, each participant received a pseudonym such as "Participant # and Gender" for confidentiality reasons. Eight participants were female and six were male. Eight of the participants were diagnosed with HIV in the U.S., while the rest of the participants received the diagnosis in their country of origin.

The participants were from different geographic areas of Africa. Four participants were born in Ethiopia, four Kenya, two Liberia, one Tanzania, one Togo, one Zambia, and one Guinea. A summary of their demographics can be found in Appendix #. Two of the participants identified themselves as college students. One person identified himself as homosexual. All participants had a form of insurance at the time of the interview. Most of them mentioned being a recipient of the Minnesota Care Insurance.

Theme 1: Lack of awareness of symptoms of HIV

The first theme captures the participants' experiences at an early stage when the symptoms manifested and none of them were aware of contracting the disease. Each participant narrated their stories from the moment of the symptoms manifested. In some of the narratives the participants reported thinner and sick physical appearances that were visible to others; however, this appearance could have been associated in their minds with the possibility of the diagnosis. Even though some of the participants described the presence of the characteristic symptoms including chronic diarrhea, fever, weight loss, and fatigue, they did not link these signs with a positive HIV status. Throughout the narratives, none of the participants were aware of contracting the disease. Due to the presence of the typical symptoms only one participant asked to be tested.

Furthermore, after experiencing the symptoms of the disease and receiving the physicians' diagnosis, a few of the participants highlighted the fact that they could not understand the circumstances of the contamination. These two

participants suspect the disease was contracted from an infected needle and are presented in the following two quotations.

One participant described the presence of the early signs of being sick that manifested after she retired from her job. The presence of the typical symptoms did not prompt her of the possibility of being infected with the virus. On the contrary, she was in disbelief about being HIV positive because she could not understand the circumstances of the virus contraction. After a discussion with her specialty physician, she assumed the transmission of the virus occurred in the country of origin while receiving various other treatments. She further elaborates the conversation with her physician who presented the possibility of contracting HIV via contamination needle.

> *"That's where {the U.S.} I started feeling not as good as I was tired, and tired and losing weight, one of our church members said to talk to a doctor because I was becoming a little bit sickly. He introduced me to a doctor. So, she {doctor} said," your blood has been found to be positive for HIV." I couldn't believe it, I said, no, no…not that I know of. So that's it. From there they sent me to another doctor that specializes in HIV, a doctor that was working in [Name] on a research team of HIV group. I went to see him, and he asked me where I was coming from. I said, I come from Zambia. And he said, well, I have to take another test and do. Just be patient. I said yes, doctor, I'm going to be patient. Finally, when I went back again a second time at his clinic he said, yes, yes indeed it's true, it's HIV and I said where*

did I get it from? I said you know, sometimes we don't know so many things that happen in life and then he also asked which country do you come from? I said, I come from Zambia. Okay, he said, you know, what? There are so many things that are happening these days. What you call HIV, especially in the third world countries it is easy to contract it. He said, especially when you go to the hospital, they want your blood transfusion. The instruments they use are not all those good ones. They…one person can be…I mean, one needle can go around so many people. They just dip it in water and then it goes just like that. And some people, women when they go for delivery, they will use some razor blades that had been used by other people and others, so it was contamination. I said it could be true. Tooth extraction is one of them again." (Participant # 2, Female)

The second participant described his initial symptoms that were not typical of an HIV infection and again his family could not associate the presence of these symptoms with the HIV status. The participant specified that when he was in late childhood, these symptoms occurred and consisted of multiple seizures and fainting that are not representative of the illness. Furthermore, according to a participant' statement, initially, his physicians did not suspect it either. The positive HIV status was confirmed when the physicians conducted additional tests. Per his comment, he is the only one in the family with HIV positive status, and his family was in disbelieve how the contamination occurred. His family suspects the infection with HIV happened through a contaminated needle in the country of his origin when he was a child.

“ Experiencing symptoms from the seizures to uh I guess passing out…I guess I went to the hospital then that’s when they diagnosed me found out what was wrong with me what was like what- why I was having those seizures and why I fainted… Yeah but, yeah, I guess my family they, did not know too because they knew I was- I lived there {Ethiopia} until I was 11 so I was fine. They think I was stuck with the needle… “(Participant # 11, Male)

Common symptoms experienced by some of the participants included weight loss, diarrhea, fatigue, and being tired. Losing weight resulted in a thinner and frail appearance that was visible to other people. However, this thinner appearance did not prompt the participants to associate it with the possibility of being HIV positive. Furthermore, the presence of symptoms and the frail physical appearances did not prompt them to ask to be tested for the HIV. Even though some of the participants noticed some of the indications of the disease, they were not linking the symptoms with an HIV status. In their narratives, a few participants highlighted other markers such as the CD4 counts and the viral load that are used by the medical team for diagnosis.

The following examples present the participants lived experiences of the typical symptoms including losing weight and feeling fatigued that are the most specific characteristics of the HIV. Many participants in this study narrated the early symptoms, and retrospectively they could not pinpoint them to the illness.

One of the participants presents the typical symptoms of the HIV he experienced before receiving the diagnosis. When asked to further elaborate on being “continuously sick,” the participant explained the symptoms manifested unceasingly, and he did not observe any signs of improvement. He is the only participant who stated that the presence of these distressing symptoms for a more extended period it prompted him to seek an HIV test. He says:

> *” And I realized in 2006, uh, when I was sick. Ya know, continuously sick, avid diarrhea, lost weight, and all that stuff. And then at the time, that I decide in November I remember, that it was 2006 November, somewhere. Uh, that uh, I decided to go and make test. So, that is the time that they found out that I’m HIV positive.”* (Participant # 4, Male)

Some of the HIV typical symptoms were manifested visibly in the physical appearance of a few participants. In the quotation below, she presents the existence of specific signs before she received the physician’ diagnosis. The participant was not familiar with the biological terminology and used the term “pimples” instead of “lesions.” These symptoms that include “lesions” that are present on the face and body along with the “thin” appearance are well known as the characteristics of the Kaposi Sarcoma. According to her statement, in her country of origin, various TV programs presented documentaries on the HIV symptoms. Knowing that these symptoms are associated with HIV, made her more aware of the diagnosis. She further elaborates:

*"Because of your pimples all over and so they already associate that with HIV because it's- they see it on TV, so long as you're skinny you're looking, you know you're whatever and you have all those pimples, so they associate you- "(*Participant #10. Female)

Losing weight was presented as a characteristic symptom of the HIV by a few participants. As can be observed in the quote below, the weight loss resulted in a visible physical change in the participant. Despite the fact, the participant noticed she had lost a lot of weight; she could not link these symptoms with the illness. Furthermore, her physicians did not initially suspect HIV diagnosis either, and they did not conduct any early HIV tests.

"Um, it was, I think in this country, in America, 2000. And for long, I was hurt there, but then starting from 2008, I started getting sick and losing a lot of weight. I couldn't eat. I was 193 [inferred: lbs.], I has reduced to 100, 113 pounds and I started going to the hospital. But they never did HIV tests, they would other tests- different, different, different tests…" (Participant #3, Female)

Another participant did not associate the symptom of dramatic weight loss with the HIV. Losing weight was perceived differently by this participant who initially believed it was due to the diet she was on. On the contrary, the manifestation of losing weight was the very first signal of a cruel diagnosis. She says:

"...{Losing weight} so fast. So, I said, oh, this is easy. Before I used to be not very fat but sometimes, I need to watch weight but when I try I don't. But

this time, it was going so fast…everybody say, …you look good. I say, right here, I am watching my weight. And then I continued. I started feeling weak. I have aches, pains at night…and I started getting sick. I get headaches. I get, especially, the stomach." (Participant # 13, Female)

Furthermore, the same participant presented the impact of the typical symptoms on her figure that became slimmer. Other acquittances noticed the change in her appearance. She emphasized the need to add a few more clothes to fit her new slimmer body size better.

"… when I wake up in the morning, I feel as if I'm wasting. I'm losing weight. Like when I wake up morning, I've lost…so my clothes became like big. It reached a time that…when people say now you're so…you are thin. I've never been thin. I started, like, the way I dress, and I was adding weight. I had to put clothes like a skirt inside, cotton one, before I put another one so as…I don't look so thin and I got worried." (Participant # 13, Female)

A few participants commented on the connotation between the decreased CD4 counts and the presence of various symptoms. The CD4 counts are markers used by physicians to diagnose a person with HIV. In the first excerpt, the participant described the impact of the symptoms on her daily life when she was not able to sustain daily activities. This participant associated these symptoms such as fatigue and being exhausted with the low CD4 counts.

"…I used to get so exhausted and so tired I couldn't do anything, I had to stop or even sit down for a minute and then I had my sister who was already

on medication so she talked to me about it and she was like, "you just go to the hospital let them check you, maybe your viral load or you CD4, maybe you're way too low, you might not be feeling sick you might be looking physically healthy but then your CD4 if it is low then you're not strong enough." (Participant # 9, Female)

In the following narrative, the person has never suspected her symptoms, and daily agony was due to an HIV infection. On the contrary, her initial symptoms were treated for an extended period with different medications that were not part of the ARV regimen. The quote below is another example of where the participant mentions the low CD4 counts that confirmed the diagnosis of HIV. It is also important to note that this participant was diagnosed with AIDS due to the extremely low CD4 counts.

"I start- my brother took me to Nairobi, and uh, they are starting- I starting, when I get sick, I go to the hospital. And I'll get the medicine, which is not like a HIV medicine. And I stay for so long. From 1994 to 2004. That is how I starting to get really sick. And um, I went to- to the hospital. And now the hospital, the doctor told me, "Oh, now you have AIDS." And my CD, for I think, I think it was 50-something." (Participant # 7, Female)

Theme 2: Cruel News:" HIV-Oooooo! I wish I was dead"

This theme illustrates the participants' emotional suffering at the moment of receiving the devastating news of being HIV positive. Each of the participants had

a different story; however, some of the common characteristics of their stories were the emotional state brought by the diagnosis news such as the immediate despair, misery, and suicidal thoughts, denial of the HIV status.

"*Oooooo! I wish I was dead"*-this quote was selected to depict the second theme because it was represented by both the characteristics of devastating diagnosis news and the denial aspect stated by the participants. All of the participants stated that they were not prepared emotionally to receive the shocking news. Some of the participants described the distressing news on them emotionally by using words such as "depression," "crying" or "suicide." Furthermore, a few participants reported their wish not to be around following the diagnosis.

Some participants were not ready to share their stories when they were diagnosed with HIV. One of the main reasons for not sharing their stories was the emotional state it would bring to them when remembering those difficult moments of their lives. Even those who were willing to share their stories, it could be heard in their voices a lot of emotions, tears would come to their eyes, some would speak faster and faster, while others will need moments of putting themselves together after disclosing those "wounds." For example, one participant mentioned the devastating moment briefly when hearing the diagnosis that occurred while being in prison and before giving birth to her baby. Another participant could not talk about the rape, while another participant was not ready to share additional information when she was diagnosed before giving birth.

The agony of receiving the disturbing news of being HIV positive impacted all participants emotionally; however, their reactions were different and are presented in the following examples. In the first quotation, the participant described the emotional disbelieved when he received the diagnosis. The participant highlights how the cruel news affected him by showing signs of depression. Furthermore, he never assumed the disease would be part of him, even though he was aware of his acquaintances being tested positively for the HIV. The following excerpt indicates the extent of the diagnosis impact on his initial denial of the disease.

> *"Oooooo! (makes loud ooo sound) I wish I was dead. When I heard it, HIV, I know before I got friends, get friends and start some of them they are- you know, HIV they had it, they live, but I would never have thought HIV, you know, I can get it!... I wished I was dead when I- I was devastated when I found out you know, I was, you know HIV positive."* (Participant # 8, Male)

Participant # 12 outlines his "depression symptoms" that he experienced after receiving the diagnosis of being HIV positive. He also described the specific moment of receiving the shocking news as dull and without any prospects for a future life.

> *"…when I got diagnosed first, I was depressed and discouraged. I felt that my whole life had crushed down, but when I start seeing other people with HIV…when I started going to … and see how people are living a vibrant life." (Participant # 12, Male)*

Frequently, the concept of “being dead” rather than having HIV was mentioned by the participants to varying extents. One of the participants reported the emotions at the moment of hearing the distressing news. She described those emotional moments by stating that her immediate reactions were “crying” and the denial of the HIV status.

> ” *I used to cry all day long… I said, I wish I would just die if that was what I had. If that was caused it, yea… She {the nurse} told me, you got to know the right place because now there is a treatment for anything…So don’t get discouraged to that. “(*Participant #3, Female)

Participant # 14 presents the dramatic moment of receiving the devastating news. This impactful moment was described by the participant with a single word “suicide.” Note, how he described that precise moment of receiving the HIV status as his thoughts immediately turned into a negative state rather than accepting it. In the participant’s statement below, there is a strong recollection of that moment that was described with vivid words and precision of the hours and the location of those moments that had changed his life forever. During the interview, it was heard the emotions in his voice that was chocking when he was presenting the destructive impact of diagnosis and relived those problematic moments. According to him, the immediate thoughts were to commit suicide. This participant did not receive any moral support to help in coping with the news of his diagnosis. He describes the negative thoughts that penetrated his mind when he is receiving the

diagnosis's news. Notice, this participant avoids using the word HIV. He refers to HIV as "this." He says:

> *"February 2001, I have been told that I have this. It was a Friday around 4 o'clock PM. Uh because myself I don't know too much about the disease uh, like I say for us when you have HIV it's the death now or tomorrow. Uh, I was about to take my own life. That same Friday…I came to the [NAME] clinic… They gave me the information I came in the bus from North Minneapolis. I was living with a friend of mine. They gave me the information and they let me go by myself. Normally somebody is supposed to take me home, stay, talk to me a lot about the whole thing so I can change a little bit my mentality regarding the disease. But nobody- and in my way back home in the bus I was telling myself "this is it, I need- I cannot handle this."* (Participant #14, Male)

After the participants received the devastating news, then HIV diagnosis became their "secret." In describing their stories, the participants pointed out the emotional difficulty they faced in thinking how to reveal their "secret" to loved ones including parents or children. One of the main reasons for the significant difficulty experienced when sharing their "secret" with their blood relatives with their blood relatives it was the stigma brought upon themselves and how the others would perceive them. The fear of disclosing their "secret" with family and friends was also linked by the participants to a withdrawal of support from family and friends.

Another reason mentioned by the participants was the “death sentence” associated with the HIV.

Theme 3: “This is my secret!”

After the participants received a cruel diagnosis and experienced denial associated with the diagnosis, they described the fear of the consequences if they would disclose their status to the immediate family members. Therefore, the third theme presents the participants’ agony of disclosing or not their diagnosis to the blood relatives and other acquaintances. This theme also illustrates a few of the participants' statements that link the stigma that separates the HIV person from the family gatherings. According to their narratives, one of the main reasons for family or community separation to occur is the country of origin societal misconception about the transmission of HIV.

Frequently, the participants will refrain from using the term HIV during their interviews despite the fact many years passed since their initial diagnosis. Instead, they would use “this,” “it” or “problem.” The use of words such as “it” or “this” here emphasizes the need to still keep their diagnosis as a “secret” rather than talking openly about their HIV positive status.

To share their HIV status with the loved ones and avoid being marginalized and denigrated by their own family, it was imperative for the participant to find the best opportunity. Finding the best moment to share the diagnosis with the blood relatives represented a challenge for most of the participants. According to some

of the participants' statements, it would be easier for some of the participants, to reveal the "secret" to their daughter than to their parents. On the other hand, one participant could not share the HIV status with his children or other blood relatives. A few participants asked their physician to facilitate the revealing of the devastating news to a spouse.

For a few participants, it was more accessible to share their positive status with their offspring instead to their parents. The participants expressed the reason for being open easier with a daughter or a son by mentioning the misconceptions about HIV transmission in their country of origin. Furthermore, some of the female participants emphasized that their mothers would perceive them as "sex workers" if they would know their diagnosis.

One of the participants confessed to her daughter but was unable to reveal to her mother. When asked why she would not disclose the diagnosis to her mother, her answer was vague, and in essence, the participant did not want her mother to know her "secret." The participant started the process of disclosing her condition to her daughter because her daughter was mature enough to understand the situation. In this quote, it can be noted how the daughter is worried about her mother whenever she does not feel well. Again, this participant does not use the word the term HIV which suggests an emotional determination to keep her diagnosis as a "secret."

> *"Was simple like we talk. Was simple. Make sure that you know kids my problem (Glance)…she was crying and when she like…when I wake up maybe I feel like sick I'm coughing like maybe coughing some time because*

it never happen this…but she scared. Mommy, "are you okay? this and this"…but for me…you not going to have a difficult life to have this happen. Yeah." (Participant # 1, Female)

Another participant stated that she was not able to share her diagnosis with her parents, brothers or sisters due to their preconceived notions concerning the HIV diagnosis. According to her, the HIV is still associated with a death sentence in the country of her origin. Furthermore, the fear of being isolated by the society was another contributing factor to keep her" secret." When asked how her children know about her status, her reply was related to the fact that they live in the U.S. where the society is less defaming to the HIV diagnosis.

" Uh, for me, even today I don't think like the, uh, my parents know. My mom passed last year. The people who know is my children who are here, but when we in Kenya I'd never disclose anything because there's something in the people, even today- when you hear of the people who have it. Because the people hiding so much. And uh, when the people know that you are HIV, people starting to separate you, like, yea like outcast or something like that. So, people- and people like, people treat you very, very different. So (clears throat), I never di- I never like, the people in Kenya, nobody know I'm HIV. So, I never get there to tell them, even my parents, like even my family- my sister, my brother [NAME]. They would like that to I'm dying the next minute. So, that the fear. For them- to tell them, "Oh guess

what? I'm HIV," there are people dying there, so I never disclose anything about that." (Participant # 7, Female)

Similarly, in the above circumstances, another participant stated that she could not find the strength to share her status with her mother. Note, how often the participant uses the negative form of the verb "didn't." Using the negative form of the verb multiple times it reinforces the secrecy of her HIV status. Not only did she keep her condition a "secret"; but also, she did not reveal any information about the medical appointments. After the time passed, the participant confided to her daughter when she was an adolescent and was emotionally ready to understand the situation. The participant further elaborates:

"In- Actually I've- up to now I've not talked- I've not told my mom. I've not talked in my mom presence. You know… I didn't, I didn't, I didn't. I would just sneak- because by then I was in that program {HIV program in Africa}, so I would sneak in and they would give us transport to and from or, someone would come and see you. So secretly I would sneak, go to hospital and come. She {her daughter} just knew, I had to open up. OK I wanted her to go to school first and finish her exam then after, that is when I told her that I was- of course she went to test (HIV test) and she was fine. Yeah, she was OK. "(Participant # 10, Female)

The following quotation presents the difficulty of revealing the status to the family members. The participant used terms such as "shame" and "special thing"

to emphasize the link the diagnosis and difficulty of disclosing to his immediate family.

> *"My daughter knows, here everybody knows. Yea my fam- my families knows. Uh, it was- yea, people use shame to identify that you can have a cancer, you can have HIV, you can flu- you can have the flu, you can have any type of diseases. It is the same. Any other people say if they are called by HIV- as if it is a special thing."* (Participant # 6, Male)

One participant perceived the sentiment of "feeling sorry" by his siblings for his diagnosis. This participant did not share the diagnosis with his blood relatives; however, the diagnosis was revealed due to some surgery circumstance. Furthermore, he confided his diagnosis to his trusting friends because they would not judge him.

> *"Oh! I have a few friends. Gay friends- they know, when I was diagnosed, uh HIV. Close friends. Very few. American. And there they, my brothers- my brothers and sisters they know- because I don't tell them. But I had big surgery on my stomach, they came to the visit me and the HIV doctor she was there and then when she talked they found out, I'm HIV positive. They feel sorry for me."* (Participant # 8, Male)

On the contrary, a participant is an undecided to reveal his HIV diagnosis to his close friends because he is not ready emotionally to reveal. According to his

narrative, his friends are aware of his health issues such as seizures; however, he could not disclose his condition.

> *"Mmm (thinking) me I, no I haven't, I'm still I guess, indecisive, but I did, they know I am sick, I guess they don't know what I'm sick with. 'Cause I did tell them yeah I'm sick I had seizures and stuff. I guess I'm like I said, I will decide, I was hoping to decide- I will tell them when, I'm ready I feel that I will tell them what the issue is, but they know I'm sick."* (Participant # 11, Male)

In a few situations, the physician played a significant role in being the mediator and conveying the shocking news to a spouse. In the following two examples there is a strong sense of a trusting relationship between the participant and the physician. Participant # 14 had faith in his physician to help him to reveal his condition to his wife since he struggled to find the best moment and the wisest words to disclose his "secret." Furthermore, the rest of his blood relatives, including his children are not aware of his "secret." He elaborates:

> *"No. I came here in {Year}. My wife arrived here in {Year}... And um, I cannot tell her what's going on, so I talked to the doctor and he asked me to come to the clinic with my wife and uh- the doctor explained her everything. My sisters don't know, my brothers don't know, nobody knows in my family. Even my kids."* (Participant # 14, Male)

Similarly, in the second example, the physician played an important mediator role in revealing the participant diagnosis to her spouse. Again, the

physician asked her husband to come to the clinic where the physician preferred to open the discussion about the HIV and disclosed the diagnosis. However, participant # 13 was not ready to share her "secret" with her children. One of the main reasons for not disclosing her "secret" for a while was the death sentence association. Additionally, she did not know how the devastating news would impact them emotionally. As time passed, she developed a closer emotional relationship with her daughter who was part of the medical staff in the hospital the participant was receiving treatment. Her daughter played an essential role in preparing her brother emotionally to receive the shocking news. The participant further explains:

> *"Now they told me go and bring your partner. And that was also so difficult for me, to go and bring my partner. I could not tell him I'm positive, come like that. I didn't want to. It's not that I didn't want to share, I didn't want to depress them {her children}. I didn't want the children…my mom will die. I was sparing them. I would like to share but I didn't know how to react, how they would be affected… Then I decided because she was working there {in the hospital}. So, I never got a chance, but I decided to tell her, I told her. From then we kept quiet. Later on, she came to tell my eldest son. She's the second born. And after some time, I came here, I went back, the younger one who had now finished college, I called him, I told him…me and your daddy are positive. He said, yeah, I was wondering because he takes medications. I said yeah, those are for pressure, for diabetic and also HIV. So, he's a big man, he kept quiet. Now you understand."* (Participant # 13, Female)

Lack of knowledge about the HIV transmission was perceived as an essential element by a participant that decided to disclose her status to her blood relatives and acquaintances. She highlighted that the disclosure of her condition to trusting friends and blood relatives with the primary goal in my mind: to bring awareness about the transmission of the HIV. This participant went through a painful and challenging process of being accustomed to the HIV diagnosis, but her knowledge at the time of infection was insufficient. Looking back at those awkward moments, she only wished to have had more information about the HIV, and the situation would have been different. She explains:

> "*Yes, I did, I did share my diagnosis with my family and my very close friends. Because I first had to look closely whom I would share my situation with. Not for my sake because I say, myself I already know myself and I'm taking care of myself but, the main reason I would share with them is to get, for them to have the knowledge and not be ignorant about the disease, at least when they know, because I always told people if I knew about HIV earlier I don't think I would be affected, or infected, because if somebody told me about HIV at a young age I would definitely know once you've been raped you should rush to the hospital the first thing and the medication the treatment would have prevented me from being infected. And if I knew my status earlier and if I had a little knowledge about HIV because, I did my presentations in school we sang music about HIV we did music festivals and everything. But it was just a song, to me it didn't mean anything. So, if*

I had somebody at that young age to explain to me, "you know, what you're talking about is this and that and this is the way it's gotten, and this is the way you can prevent it. I don't think I would have gotten it." (Participant # 9, Female)

Participant # 12 offered an explanation why persons with HIV in his country of origin would not disclose their status to the relatives. In his opinion, one of the main reasons is the lack of family support for an HIV positive person in his country. Participant # 12 use of the word "leprosy" is interesting and powerful because of the segregation effect that might be felt by the HIV person. Furthermore, he compared the HIV segregation impact to another infectious disease called "leprosy." Participant # 12 comments:

"And most people die in Africa because…when it became positive, this and that…you know, families, they didn't get family support. So,…People ostracized like leprosy in the 50's and people, you know, they didn't get family support, even though if you're going through problem and you get family support, there family support service is better can give you ….but most would not even get their family support." (Participant # 12, Male)

Similarly, Participant # 3 points out the presence of misconceptions about the transmission that forces many people with HIV not to disclose their "secret." The fear of catching the virus via sitting next to a family member and the

association between HIV and death sentence persists in the country of her origin. This extract accurately captures the existence of misconceptions that lead to a separation of the family and unwillingness to reveal their diagnosis to the family.

> *"Even your own family is afraid of you. Yea. Most of your family will be afraid of you, that don't know about it, 'cause they don't want to die. They know it's something that kills, it has no cure. So, if they don't know that just by you sitting by me will not make you to have it, they get afraid, they don't want to die."* (Participant #3, Female).

Use of word "outcast" in the below quote suggests the blood relatives are distancing themselves from the person who is HIV positive and giving a sense of the possible isolation would have been felt by Participant # 10 in case she disclosed her status. As seen in the previous examples, this participant has not revealed her positive status to her blood relatives due to the fear of separation that would have occurred. When asked if she disclosed her diagnosis to anyone in the family her answer was affirmative and occurred years later when her daughter was emotionally prepared to receive the shocking news. This participant further describes a similar situation where the family isolated a friend of hers. She elaborates:

> *"So, anyone who had HIV was considered an outcast. As if no one wanted to come to be with you to even, if they knew they wouldn't even come to my house, my relatives. If they knew, my friends would not even come. You*

know, sharing cups- even in the house like usual. There's a friend of mine who said she talked to her brother, it was the brother talked about you know, about her status, the brother gave her, her cup, a plate and a spoon and were kept aside. This is your only brother, kept aside. Because you know you're not supposed to share, you're not supposed to share. Yeah, so those are some of the things that made us just shut up. You wouldn't talk about it. Because now if you talked about- the fear of being, of being um- of them cutting you off. So, you'd rather just stay. Yeah." (Participant # 10, Female).

A few participants echoed the lack of family support for a family member who is HIV positive. One participant presented her opinion about the plausible reasons for the family's behavior. According to her statement, the presence of misconceptions about HIV transmission results into family separation. This participant uses powerful words such as "scared" or "abandonment" to present the situation at the family level and how the family distances themselves from the HIV person.

"Oh… NO….in my culture NO… because if you talk about you it is a high risk of being abandoned by the family. The people will run away from you it is a big taboo to talk about! Abandoned because some people will think if you are close to them you will give them the disease, you will contaminate them. So, close family or your parents, friends might be scared of you because now they do not want to be too connected to you… they are scared

of you… and it is better for them to be away from you…including the family." (Participant # 5, Female)

Theme 4: The impact of stigma: "Stigma and HIV are brother and sister"

This theme quotes one of phrase used by a participant *"Stigma and HIV are brother and sister."* This quotation was selected to denote this theme because it was the most significant, concise, and explanatory of the stigmatizing situations faced by the participants. This quote also tried to present the magnitude of the defaming impact of HIV status on the participant. This theme emerged without prompting the participants to discuss it. Many participants used the word "stigma" during the interviews. They also described the stigma associated with their HIV positive status using other words such as "isolation," "separation," "abandonment."

The participants attributed the stigma effect due to the existence of misconceptions about HIV transmission in their country of origin. Most of the participants perceived being stigmatized in their country of origin due to their disease. Furthermore, some of the participants mentioned the association between the HIV status and stigma in various cultural circles in the U.S.

The participants at different levels perceived the stigma associated with the HIV status. Firstly, at the societal level, participants linked the stigma of being HIV positive with their country of origin cultural norms and values, and the lack of a public discussion about sexual reproduction. Secondly, at the individual and societal level, the participants presented the linkage between misconceptions

persistent in their culture and the HIV transmission. Thirdly, at the family and community level, the participants connected the misconceptions of HIV transmission and the lack of family support to the fear of disclosing their HIV status. The sub-themes that emerged from their narratives were:

a) Linkage between stigma and their country of origin cultural values
b) The landscape of societal misconceptions about HIV transmission in their country of origin

a) Linkage between stigma and their country of origin cultural values

The first sub-theme highlights the participants perspective of the role played by their country of origin cultural norms and values in the association of stigma with the HIV status. When asked if it is acceptable to talk about HIV in their country of origin, all the participants had a negative response. For instance, one participant clarified the reason why in the country of origin culture is impossible to discuss open the issues related to sex. Additionally, many participants mentioned that they were not ready or willing to share their positive status with acquaintances or co-workers due to the impact of stigma. When further asked to clarify the effect of stigma, most participants stated they felt isolated from the society due to their positive status.

Participant # 10 clarified how the process of stigma developed in her country of origin despite the fact most people would not disclose their diagnosis to anyone. She stated that an HIV person would be defamed in a bus by her/his thin appearance and the presence of “pimples” that are also known as Kaposi’

Sarcoma. Due to the presence of these symptoms that person would not be allowed to sit next to another person on a bus ride. The following quotation vividly captures a sense of shame a person with HIV would perceive concerning his/her condition.

> *"The bus yea, the bus comes, and everybody knows this one, must be HIV… so long as you have pimples but it will be said that people with HIV are skinny, the have pimples all over, their lips change, their skin texture becomes darker, so yeah, when you just come in they analyze all those (laughs) 1 you're dark, 2 your lips are red, 3 you have all those pimples, you will not sit next to me. They will not tell you HIV, but they will try and tell you not to sit there. And you see you can't refuse because now everybody in the bus will look at you and say you can't say like say I will sit and let's see what you do, because maybe the next person also feels the same. So, they can even gang at you, so the best thing is just stand and wait for your destination, or maybe you're going to the hospital."* (Participant #10, Female)

Furthermore, another participant in his narrative pointed in his culture in the country of origin is not common to speak freely about sexual-related topics. In the statement below the participant further elaborates about his culture and expresses his opinion why it is so difficult to converse about sex-related issues.

> *"When people is like because ….my culture sex is not public discussion. People cannot sit down, you know, and open forum and discuss about sex*

so sex is like a private……so people kind of keep it as a secret and if the people know that you are HIV positive, the treatments are very high…So I mean, like my culture is, you know, HIV I mean, it has a long, long way for people to get to know that you know, people…" (Participant # 12, Male)

" It is not easy to talk about HIV because most people are stigmatized out of it. When you say you're positive, people will distance from you, people will feel like they wouldn't want to share even just a cup of coffee with you because the feel like you're dying. So, it's not that easy to share it. And that stigma is what is bringing people even down." (Participant # 9, Female)

Some participants illustrated disgrace and isolation as the effects of stigma perceived at the societal level. For example, in the quote above the participant highlights the isolation level that the society will add on the participant's shoulders due to her positive status.

Participant # 6 used a powerful, defaming, and insulting comparison between HIV positive people and "animals." He vividly describes the disease as the principal reason that resulted in a separation between people in Africa. He also mentioned that the situation changed over the years where the HIV people do not feel as stigmatized as before.

"Oh before, they used to take you as if a wild. Wild beast animals, before. Everywhere in Africa even. But not now, now- the activism work is done, nicely, everywhere. The graph is- not increasing, decreasing. The

segregation is decreasing. You can sit, you can enjoy, you can eat. You can drink with them, no problem..." (Participant # 6, Male)

Furthermore, one participant pointed a different aspect that connects taking ARV medications and HIV stigma. She stated that some HIV positive people might not take their ARV medications due to misbeliefs that persist in her country of origin. In this extract she emphasizes the possible rational why various individuals diagnosed with HIV might not be adherent to the ARV.

"… and there are so many Africa- like, some of them do not take their medications. They will say, "Hm, they told you you have HIV, I don't think you have it, but the moment you start taking HIV pills, you gonna have it" [as in: paranoia that the medication carries the infection]. That's why they don't take their medications." (Participant # 3, Female)

b) The landscape of the country of origin societal misconceptions about HIV transmission

This sub-theme presents the participants' opinions about the presence of the societal misconceptions on the HIV transmission in their country of origin. Numerous participants presented their stigma experiences through the social misconceptions of the HIV transmission. Examples of societal misconceptions provided by the participants included transmission method via shaking hands, sitting next to someone, or sharing the same dishes. This sub-theme also illustrates the fact that these social misconceptions in their country of origin

affected the participant' lives at the individual and interactional level. A few of the participants highlighted that misconceptions persist in the U.S in some of the African-born individuals.

One fundamental societal misconception in their country of origin highlighted mainly by the female participants was labeling them as sex workers. Several of the female participants expressed that the community of their country of origin would defame the women who were HIV positive and would portray them as sex workers. Her use of the word "prostitute" in this extract highlights a situation where the female participant is stigmatized due to the HIV diagnosis.

> *"No, they talk to you, but you just a subject of gossip. I mean…I don't know they feel that once you have HIV, you have been a prostitute, have been sleeping all around, and that's how you got it. That is one of the main point of gossip- "(*Participant # 3, Female).

Similarly, for Participant # 10 the societal misconceptions in her country of origin forced her not to reveal her diagnosis to her mother because she would be considered a "prostitute."

> *"Actually I've- up to now I've not talked- I've not told my mom. I've not talked in my mom presence. You know, OK, as I said back then, HIV was labeled like. If you're HIV you're a prostitute. If you're HIV you're- I don't know they just, they associated HIV with prostitution. So, anyone who had HIV was considered an outcast."* (Participant # 10, Female)

Another societal misconception that emerged from the interviews was that the disease could be transmitted via a meal. It was highlighted by different

participants that there were situations when the HIV person would receive a separate dish to ensure the disease would not be spread to the other friends or family members. Furthermore, shaking hands with an HIV person leads to the transmission of the virus was another societal misconception that emerged. Following are examples of the societal misconceptions about HIV transmission.

In the first example, a participant explained that the role played by education in understanding the transmission of HIV. According to the participant statement, these societal misconceptions vanished from her mind once she received the appropriate educational information about the transfer of the virus.

> *"We thought it was like contagious just by shaking your hand or sitting with you. We didn't know it was contagious in other ways. Like seizures, we will have seizures, we are afraid we said- if this touches you, you're gonna have seizures. So, like, someone is having seizure, yea, you would start running away from them. But when I started working in the medical field, I knew it wasn't like that. Yea. It's just the education that's- Africa"* (Participant # 3, Female)

The same participant also mentioned that some of the societal misconceptions about HIV transmission continue to exist in her community. Because these misconceptions persist in her society, the participant would not disclose her status to her church friends and acquittances. Revealing her HIV status to the church community would result in distancing her from that community. Additionally, she pointed out the role played by segregation in an HIV person's life.

According to her, the solitude of a person leads to depression and ultimately, passing away.

> *"As I said, up to now, if I would tell people in that church that I have HIV, they may not sit on the same bench with me. Yea…They don't know. They feel, even as I said, the way I'm talking to you- they would get HIV, by sitting- or they can't even shake my hand or they can't even, you know? That's how I used to feel from my own personal, um, something- that's how I used to be. Yea. But since I got to know about it, I don't care anymore. I can sleep on the same bed with- with someone with HIV, I mean, not to have a relationship, but we can sit on the same bed, we can sit at the same table to eat. I know that's not the way to catch it. But if you don't know, people that don't know, they get afraid of you. Then you get isolated. And that's why most people die in Africa. 'Cause you are isolated, you don't have friends."* (Participant # 3, Female)

At the society level, especially when the HIV was emerging as a disease on the African continent, one of the participants pointed out the inability of stakeholders to further understand how the HIV was transmitted. Those misconceptions perished; however, the participant wanted to highlight the origins of them. This misconception is described by the Participant # 10 in the following example:

> *"And in those times- people- those days, people were being buried in plastic bags. Yes, yes, they were being buried in plastic bags. Because no one wants to handle- you know, it was- it was even from- the medics themselves.*

The stigma from up to down. Yeah from up to down…It was a lot of stigma. A lot of stigma. A lot of stigma." (Participant # 10, female)

Other participants reinforce the above societal misconceptions that HIV is transmitted by touching as they comment:

"…So, they are afraid even to touch you, they are afraid. Because they need more explanation about the whole thing." (Participant # 14, Male)

"A stigma is if I were back home and if people know that I'm HIV positive I would loss lot of friends, I mean, people would not like to do business. If I were teachers people would not like to interact with me, I mean, not even be a teacher because people would think that you know, by them talking to me like I'm talking, they're going to get infected." (Participant # 12, Male)

"They feel- they make me feel like I'm- so if they touch me like that, they can catch it. Even they live in America, all my friends is American. See? I learned that. I don't have to tell." (Participant # 8, Male)

Theme 5: The power of spirituality and prayers

This theme represents the world of participants' spirituality and its main impact on their existence. Throughout the interviews, the participants invoked God's divine powers in helping them to go through those difficult moments. The strong beliefs in the Divinity offered them strength and support in awkward situations such as diagnosis and living with HIV. According to their statements,

God continuously plays an essential role in their lives. Participants also discussed the healing powers of prayers and its impact on their daily lives. For example, one of the participants highlighted the fact that her strong belief in God and daily prayers allowed her not to take ARV medications for years.

Some of the participants defined spirituality regarding religious activities they were taking part. Religious activities mentioned during the interviews were singing in a choir, attending Mass, engaging in church events, or studying the Bible together. The participants do not want the religious community to know about their HIV positive status, because the disease is stigmatized. Even though some of the participants belonged to a religious community and shared their disease state, they would be very careful to whom they disclosed their HIV positive status. Furthermore, if they shared their HIV status in the religious community, it would be a person whom they trusted, and in most cases, they shared the disease state with another HIV positive person who could understand and not judge them.

Some of the participants mentioned the importance of their spiritual life and deep connection with the Divinity for their wellbeing. The following cases present the participants' perceptions of attending Mass/church services and also prayers. In the first example, the participant explains how she found strength in attending church and prayers.

" Oh yes. The church and the prayers, you know, when we pray things are different from most people. When you're trusting God... You have to have

that faith in the doctors and yourself and power from anything." (Participant # 2, Female)

In the second example, the participant explains how the healing powers of prayers transformed her. Additionally, this transformation was observed by her friends who could be seen it on her face/well-being. She says:

"Yea. Every time I pray, I said, even my friends, people from abroad, they would see me- I mean, my pictures, "Why you not working? Why you look better than some people that working?" I said, "Well, it's God. It's just by the grace of God I'm living," yea." (Participant # 3, Female)

In the third example, the participant talks about a Christian life filled with hope, support, and love for each other. The participant discusses the help she received from her church to go through difficult periods of her life. She has established a connection with God and used this connection to facilitate her wellness. The participant discusses her Christian faith such as going to church, praying, supporting those in need, and believing in God, who loves them. Note the frequency of her use of the word "God" or "He" in the following quote. It is clear this person believes in the miraculous powers of God who is the center of her universe.

"My driving force is that I'm a Christian. We believe in life after and in our church also we teach health. To eat healthy. I'm a 7th Day Adventist…We support people with HIV but some people there's still stigma. So, the church supports us so much. It gives us hope. We understand that when your day

comes to die, is when God has decided that day for you. Nobody and nothing despite all that and I believe that. All this I've gone through, God has been there with me. I'm still walking with him and I will live my full life until when he said I'll die is when I'll die. So, support…when people have hope, you hope for something better than this one, we wonder when because since I was small we say God is coming soon. He has not come, but I know he's there. Everybody believes in something supreme." (Participant # 13, Female)

The above examples illustrated the connection with God through church and its related activities. On the contrary, one participant feels he does not have to go to church to pray. Indeed, he connects with God via a portable Bible that he listens to whenever he feels. He developed a direct relationship with Divinity via the portable Bible and the prayers. The participant points out his family isolated him because of his sexual orientation and diagnosis. The prayers have a healing effect on him. He elaborates:

"Oh, even though I'm no sinner, I'm not perfect, I believe in God. Deeply. I listen to Gospel, music. This is keep me go- keep me everything- spiritual. So, it's the bible which- Keep me going. Even though I'm gay. This is- It's what- Kept me going. I feel sad I cry, I'm not accepted, you know by, my own family my siblings, because I'm gay and a lot of things happen to me.

Abused all kind of ways and everything. I don't play victim. I don't want to do that. I give those people power" (Participant # 8, Male)

The miraculous powers of prayers helped one participant to achieve many milestones from the career point of view. The participant explains one of her dreams was to live in the U.S. The previous immigration laws restricted HIV positive people to immigrate to the U.S. However, the change in law permitted her to immigrate in the U.S. and fulfill her dream. In the quote below the participant explains her relationship with God who had the power to ease her way to the U.S.

"Yeah, I'm a born-again Christian. I believe in supernatural powers of God so, my faith has brought me this far and I always tell my friends that no matter what you're going through, if you have faith in God and Mark 11:23 is always my verse that says, "whatever you believe in, if you have faith, know you have it and you will get it." That has always been whatever is maneuvering around me and what is making me get to where I want to be. Because before I came to the United States I used to tell my friends when I got my job, my first job in Kenya and everybody was asking "what's your vision?" or "what's your plan?" I was like, this is my stepping stone I'm going places and when I applied for my green card to come to the United States, I just said I pray that God would allow me to come to the United States before Obama left being the president because before he came into presidency you couldn't be allowed to come to the United States when you

are positive so, when I knew about my status it was way back and then I wanted to come to the United States and then this was a barrier as like, so is this going to block me from doing what I want to do? But you see chances of winning the lottery is a 50/50 chance, you might win it, or you might not get it, but I had the faith that I was going to get it, so I wanted to get it." (Participant # 9, Female)

Some participants observed different spiritual changes in their lives after the diagnosis. The following examples illustrate these changes including an increase in the number of prayers, a deeper relationship with God, and a modification of the sexual behavior.

To illustrate, one participant noticed changes in his spiritual connection with Divinity after his HIV diagnosis. He increased his prayers that allowed him to feel closer to the Creator:

"Uh (thinking) I guess more as spiritual, I would say prayers as to one thing. I never really prayed as much- I wasn't really a- I didn't pray as much as I did once I got this disease, I tended to start praying I guess how everyone would call out to God when in need. So I did, yeah I guess prayers…" (Participant # 11, Male)

The profound connection with the Divinity made one participant to change her sexual behavior. The quote below illustrates the changes she made in her life after being diagnosed with HIV. This modification in her sexual behavior was seen as described as abstinence from sexual intercourse. The participant explains the change in her sexual behavior was due to the Christian faith. She elaborates:

> *"OK. I'm a Christian and so yeah, OK. I pray a lot. I really pray a lot so- Um, I think being a Christian and having that faith and knowing that life is precious and um- of course for me after I got- after I knew my status then I stopped like, like having multiple partners because I knew, OK, one- my Christian faith wouldn't allow it. Like it was wrong to, to go around or whatever. And then, still it helped me to not have those multiple- those -um- reinfections. Yeah, re-infections. So, I stopped you know, the reinfections. And so, I think also being a Christian kind of tamed me. Yeah? Tamed me like uh, having those Christian values in me made me I would say made me healthier. Yeah. Yeah."* (Participant #10, Female)

In addition, another participant explains the impact of Christian faith on his sexual behavior. After being diagnosed with HIV, he stated that he became more aware of the disease and how it is transmitted. He initially explained the fact that in his country of origin a man could have multiple wives. However, after diagnosis and respecting the Christian sayings, he would have only one wife and will not have sexual intercourse with other women.

"…uh, you know, in Ethiopia, you can marry two, three ladies. To some extent- I believe in one god, I'm a Christian. I was, and I am too now. I gave myself to God, I am careful now. I am not drinking, I am not doing bad things. I have do have a wife at home country. She was checked- she was the same with me, but she's taking the medicine, no problem with me. No problem with her, still no… But I was teaching before I came to know myself, you know… I was telling the people not to marry two, three wives. Not to do such and such things. Not to do bad things with prostitutes womans. Eh, and not to drink more than needed. Not to drink- not a single, no- but not to drink more than needed. Even eating more than needed is not good. I'm careful- with that. I'll not drink, I'll not smoke. I'm taking care of myself. This is what I am doing." (Participant # 6, Male)

Another participant explains how his strong beliefs in God alleviated this journey. After diagnosis, he looked at God for spiritual healing and support. According to the participant, he received dual support: from Divinity and the medications.

"So, when I put all those things together with my faith in God that help a lot. That helps a lot. And I was right, because eighteen years now, I was thinking that "this is it" "it's the end" but it's eighteen years now I'm very strong, I'm not sick. I'm not sick at all. So, my faith helped me a lot and also the medication helps a lot." (Participant # 14, Male)

In the quote below the participant stated the positive impact of prayers on her. The strength offered by the prayers facilitated more natural management of the side-effects she was experiencing from chemotherapy. Furthermore, the participant talked about the necessary force she received from Divinity when she was not taking ARV medications. Similar to the previous participant, this participant believed that not only the ARV medications played a significant role in her well-being; but also, so did the Divinity. She says:

> *"I think uh, part of my life, um, I think to be a Christian and to have faith because when I through- when I got through this chemo it come to the point that I get very sick that time. I was telling the doctor, I don't feel like I want to take Chemo anymore because now I get sick and sick. And the doctor was like "no, you can't stop your chemo because of uh, some reason, uh you have to finish." But I have faith I was praying God, I was trusting God because that day I had to have HIV, I have AIDS at that time, I think I had HIV I didn't even have AIDS. Every time, I feel like I'm sick, I was (smiting?) God every day. And God I know, I can do it this- there's no way I can afford the medicine. Do you know I stayed 10 years without taking {ARV} medicine. From 1994 I come to take medicine 2004. The whole time is faith, when I get sick I would call my pastor, we would pray and I think yeah, the belief, only the faith, that faith just to believe, it helped me so much, even today. That is how I don't think medicine only, the medicine also I have with God." (*Participant # 7, Female)

The same participant also explained the significance of a spiritual support group. Not only during those meetings they discussed and read the Bible; but also, they provided spiritual healing that eased the way through their lives. Furthermore, she sees herself as taking an additional role in educating her religious friends on HIV transmission. In the excerpt below the participant tells:

> *"We have like a group of women, or a group of people we are, we are praying together. Also, I tell them it's good to be very wise, even the Bible talk about the wisdom. You have to be wise, don't be careless because you are Christian. Things happen in life so be very faithful to who you are, be faithful. Even me I talk, even the couple the people, the young- the people who a young even them I talk to the couple I say "be very careful" This is a disease, HIV is a disease and it doesn't know who you are so, you get it. Because when I have it I was Christian. So, you can get it anywhere. So that is how me I educated people "please be careful".* (Participant # 7, Female)

Theme 6: The significance of taking ARV medications: "*To exist I have to take the medicine*"

This theme represents the participants experiences regarding their ARV medications. Six of the participants were diagnosed in Africa and initiated on ARV in Africa, while eight participants received the diagnosis in the U.S. and started on medication regimens in the U.S.

This theme denoted by the phrase, "*To exist I have to take the medicine*" was the most significant sentence that represents the essence of the main reason for taking the medications. The participants are "alive" due to the medications, and this concept emerged from all of the interviews. Although at the beginning of treatment, some of the participants mentioned the inconvenience of the larger tablet size or "pill burden," they continued taking the prescribed ARV medications that prolonged their lives.

Regardless of where they began treatment, these two groups presented similarities including the experience of side-effects, "pill burden," symptoms that prompted to start ARV treatment, a larger size of medications, and secrecy about taking medications. These experiences broke down into two sub-themes:

a) Initiation of treatment in Africa

b) Initiation of treatment in the U.S.

a) Initiation of treatment in Africa

Six of the participants were started on ARV medications in Africa at different stages of their disease. According to their statements, a few participants were initiated on ARV medication more than two decades ago. Since such a long period lapsed, some of them could not remember all the details for the initiation of the treatment.

A few of the participants recollected various reasons for the start of the treatment such as low CD4 counts or feeling weak. The following examples present the participants' experiences at the initiation of ARV treatment that was

due to the decreased CD4 counts. In the first quotation, the participant highlights the fact that the physician did not prescribe any ARV medication when he was diagnosed with HIV. When the CD4 counts dropped to a specific level, the physician initiated him on medications.

> *"… Yea, there at that time, they have a policy there that they need you- count, col- ya know, your CD4 count -to be a level of less than 300 or something. That is the time that you will start the medication. They will not start the medication right away. After I diagnosed and found that I'm HIV positive, ya know, I stayed more than 3 years without taking medication. Because at first, my CD4 was high, and then they say, no you don't need to take medication right now... And it was in total d- uh, ten, I remember it was 2010 that I started my medication in Africa, back home."* (Participant # 4, Male).

Participant # 9 remembers exactly the low CD4 counts that contributed mainly to the initiation of treatment.

> *"they found my CD4 to be at 139 and they asked me if it was a good idea for me to start medication, then I opted to start medication."* (Participant # 9, Female).

On the contrary, in the quotation below, the participant cannot remember the exact CD4 counts. However, this participant recollects the specific details of the symptoms that were associated with the low CD4 counts. To avoid any

inconvenient questions about her visible symptoms, she would say the symptoms were due to an allergic reaction to food.

> *"…was around 77….I don't remember 50 or 70..somewhere there. And they started to say they start…medical treatment. The skin was peeling off. I was so bad. I used to tell people… I ate goat meat and I reacted. I had…..I looked terrible. My skin was so dark is peeling off…like here…even here like …" (*Participant # 13, Female)

The main reason why the participants took ARV medications was different for each participant. However, it was collectively described as sustaining their lives. Participants used simple and powerful words such as "being alive," "staying," "to exist," "to live" to explain the motivators why they take the prescribed medication regimen.

The participants' reasons for "being alive" due to the medications are expressed in the following examples. In the quotation below the participant is reinforcing the concept that these medications continue his existence. Participant # 6 says:

> *"To exist, I have to take the medicine. The medicine is to limit the amount of- [corrects himself] to increase the amount of antibodies in my body. So, I have to take to exist in the world."*

To better explain the rational for taking ARV medications, she compares the process of taking medications with the process of eating. She comments:

> *"Because I know it helps me a lot. I know it's important like when I take it- that is how my mind, I think in my mind like, if I can't live without food, this medicine also helps me for living. So now I see how many years since- so I feel like, it's a part of me, so yeah I take serious- I take serious about medicine."* (Participant # 7, Female).

Another motivator "to be alive "expressed by one participant is the desire to live the moment when there will be medication to cure the disease. The example below shows her strong will to achieve this milestone. As her current dream is to share her story with her grandchildren. She also aims to explain to them how the ARV medications changed her life. The driving force for this participant at this stage is to be part of that magical moment when the medication will cure the HIV. Participant's # 10 use of the terms "I want to live!" twice suggests a sense of partnership between the participant and the ARV medications. This participant emphasizes the important role played by the medications in her life. Clearly, Participant # 10 transmits an important message that is "she wants to live!"

> *"I want to live! (chuckles) I want to live! I want to be there to tell the story. I want to be there to see the [grants?] you know the cure, to be there. And we can be the pioneers to say you know we were there then, and now the medication is here. I want to see that. That's what I want to see. Yes! That's*

what drives me. Yeah, I want to continue being healthy and live until that day when the medication will be there. The treatment."

Another motivator for taking ARV medications is to acquire a regular life without HIV symptoms. One participant explained the importance of taking ARV through the systematic changes produced by the medications at the metabolic level. The participant observed these changes in the way he was feeling and not experiencing the symptoms of the disease. In other words, the ARV helped him to achieve a regular life and ultimately, sustain it. He presented the differences in symptoms before taking ARV and after taking ARV. He elaborates:

"Uh, yea. It's a really taking medication, ya know, as somebody who's sick. Ya know, taking medication is, ya know, it help a lot because I remember before I started my medication, I was really sick, ya know, continuously sick today, sick tomorrow, sick another day. But until I started my medication now, ya know I'm like, normal person and yea… I feel normal, yea…Never been sick like, ya know, that I was before- before I start the medication… the reason why I say it's working for me well, uh, now I'm not feeling weak. Ya know, I'm not feeling tired. I'm not feeling sick, like I used to be before I started my medication, and that is a big difference. Yea, that is a big difference, I say… Uh, as I earlier mentioned to you, the difference is before I started my medication, I used to be sick, I used to be tired, feeling weak, having a lot of diarrheas. And ya know, knowing that I'm not feeling OK, I'm

not normal. I'm very tired, I'm weak and ya know, many time I used to be sick, ya know. But since I started my medication up to now, all that are gone. It's not there anymore. So there is a big difference that being on medication and not being on." (Participant # 4, Male)

On the other hand, one participant noted the differences between her current and previous ARV medications regarding the tablet size. For Participant # 10 the current regimen is much more appealing to take it since they are smaller in size as opposed to the previous ones that were much larger and difficult to swallow. The participant uses the term "tiny" repetitively that might suggest an emotional reaction to the regimen.

" Um, one, OK in Kenya, back in Kenya the medication, what I used to take was very thick and very big (Laughs) and you know just swallowing that like every day, it was hard. But here they, very tiny! Very, very, tiny medication, very tiny medication so, yeah, it's easy to take. And, so far I feel, I feel, I feel better. I feel good so. I don't know I think here the medications are better. They are far much better." (Participant # 10, Female)

Another contributing factor that inconvenienced the same participant was the massive number of medications previously taken. Fortunately, the number of medicines reduced over the years and made it more feasible for the participant. She says:

“I used to take- like- is it six? Six or seven medication. I can’t even remember don’t even ask me the names but there was so much. So that’s what we used to take then you know slowly it dropped to, I think three, and then before I left I was taking two. Yeah, but back then it was so much.”

A few of the participants pointed the emotional challenges they faced when the physician started them on ARV regimen. The challenge was to keep the medication as a “secret.” Even though taking ARV medications was vital for the participants, one participant recollects how she used a private space to take ARV medications. Once she shared her secret with her daughter, she did not have to hide her medications anymore.

”Taking medication, I would sneak to go hide by the toilet to take my medication (chuckles) because I didn’t want anyone to see. Yeah.” (Participant # 10, Female)

Similarly, Participant # 13 experienced the emotional challenge of how to keep the medications as a secret. She asked the medical team to use a different package for the medications she was taking. This camouflage allowed her to continue taking the prescribed regimen and not sharing her secret with her children until she was ready emotionally to talk to them.

"But I used to hide them so well. The first time when I was started on medication she {her daughter} was in the house. I told the doctor. Please repack this. Can you repack my medication because the girl was in the house. I have two boys and one girl. So, they repacked." (Participant # 13, Female)

Some participants described experiencing different side-effects that occurred at different stages during treatment. Some of the participants mentioned the side-effects mainly at the initiation of ARV medications. Even though the participants highlighted they experienced various side-effects, they continued taking ARV medications. Depending on the circumstances, the drug that produced the side-effect might have been changed or discontinued. As presented in the following examples, each participant presents the side-effects experienced. However, no common side-effect emerged from the interviews.

In the quote below the participant described the symptoms developed that was an indication of diabetes. The medication that caused this side-effect was changed to a different one. When asked if the participant continues to take antidiabetic and ARV medications, the participant confirmed taking both of them.

"… I remember before they switched to the medication that I'm now, the two, uh, the one that- the three that here I was using, yea, uh- if- it increased my diabetes…Yea, making me have diabetes. But I don't know before that I have diabetes. And then like, making me test it, drinking a lot of waters

and getting me like, good rest. And so, when I go and see my doctor, my fa- family doctor, they tested, and they found that I'm- I have diabetes. And that medication is not good with the diabetes, so they had to switch it to the new one…" (Participant # 4, Male)

Participant # 7 noticed the presence of a tumor due to a medication that she was receiving. Another symptom of the side-effects experienced by the participant was the presence of pain that signaled to go to the hospital. The presence of these side-effects on her prompted the medical team to discontinue the medication that caused the tumor and initiated another ARV medication and chemotherapy for lymphoma.

" Although now the medicine is starting to help me, a little bit. Because the CD before I think was 50, now it's starting to be like 70. So the medicine's starting to help me a little bit, but I have side effect. So I keep telling them, "Oh, since I started this medicine, something happened. Now I have a- I have something starting to grow and there's something to happen- now I have a, I think I have a side effect to this medicine…I told him, "This thing is still- it's pain. Can you take me to the hospital to check what is-what is happening?" When I went to the hospital that is how the doctor was like, "Wow, you have lymphoma and uh, this is very serious. You have only three months- spreading to all-" Well, because I have this thing like the whole year, this thing was still there. It give a lot of people- they have a side effect,

it's lymphoma. So, then they start me the chemo and treatment…even if I have a, like even in the beginning there was like a, I have some side effects but then the doctor would change immediately when I said something is going on." (Participant # 7, Female)

Another side-effect described by a participant was excruciating muscle pain that resulted in changing the ARV medication. Not only does the participant present the side-effects; but also, does she describe the impact of the side-effects on her daily duties. The side-effect was an obstacle to sustain a normal life for this participant. She further elaborates:

"So, I took the medication for a period of a year but then the side effect that I first had with my first type of medication, I can't really remember the medication name, my muscles were stiffening so hard that I couldn't carry or do my daily household chores with ease because if I did laundry, because in Africa we do laundry manually, so my veins would be very painful so after that they had to change my medication. So then when they changed my medication it went well. My CD4 improved." (Participant # 9, Female)

Putting on weight disproportionally was a different side-effect experienced by one participant. The participant explained the impact of putting on weight on her figure that changed. Due to a change in the medication the side-effect did not manifest. This participant also here explicitly connects the side-effects of the

prescribed regimen with her “funny” appearance. She ironically presents herself in this extract, rather than in a depressed mood. Participant # 10 powerfully describes the side-effects she has experienced.

> *“I felt better but uh, I think when I stared my body, my body changed, you know? My body changed as in I had- My boobs were big and my hips sank in I was looking... Yes, yes, yes, I can say I gained weight. But, not all the parts of my body yeah, it was the up- the upper was- and down, you know my hips, sank in and so, it was I was looking funny. I was looking funny yes. Then they had to change, I think they had to change my medication. There was something wrong with the medication, so they had to change one of the medications. Then I changed back, I went back to normal. Yeah.”* (Participant # 10, Female)

Over time, the same participant noticed other side-effects that she did not mention earlier. She remembered a few side-effects that are presented in the below excerpt:

> *“Yes, in the past there were various. When I was starting the, the first medication I had numerous, numerous and so at one point they had to change my medication…You know, the change of the body. Uh, I would have itchy, itchy, itchy, skin. Yeah, and so, the very first- it was bad until they had to change my medication. And after, after they kind of reduced, the headaches, the itching still continued, but not as severe. But so far, now, nothing.”*

Participant # 13 had to be switched to different ARV medication when she experienced various side-effects over the years. For instance, she initially had an allergic reaction to the ARV medications she was prescribed. When asked if she could remember the name of the medications she was taking, she responded no. She described the allergic reaction through the presence of itchy red spots on the skin and the rash. The presence of an allergic reaction was attributed to the ARV medication that was discontinued.

> *"I started getting big red…pimples…Yeah, but not like pimples which are sick, like pimples which you are reacting….allergy…Yeah, itchy….So they had to stop those medications and still when they give me this one, my body didn't take medications very easily so they had to use some medicine which was very expensive for that time…So I said they have to give, they give me medicine to make me cope with this medicine. Like I would accept. They changed the medication."*

The effect of ARV medication on weakening bones and increasing the risk of bones breaking was another side-effect mentioned by the same participant. She says:

> *"…they told me also because this medication I can tell you, it has a toll on our bones…teeth. Yeah. Osteoporosis…YEAH. And the teeth. When I*

found out I'm sick is when I started going for my teeth knock out...it's going so fast. Yeah." (Participant # 13, Female)

The same participant felt that the ARV medications decreased her memory capacity. Looking back, she thought that she started forgetting things in a daily routine since she was diagnosed with HIV. She attributes the reduced memory capacity to the ARV medications she was prescribed. Even though the memory loss was her concern regarding the use of ARV medications, she did not discontinue her medications. She highlighted that this side-effect was experienced by other friends of hers who are also HIV positive. Participant # 13 says:

"One time I remember, this year I remembered….recently…you know, one thing, this medication interfered with my memory. That's one I know. It's interfered with my memory. Since I got sick or…whatever, it interfered. This interferes with memory. Even before I started taking medicine there was a lapse in my memory like I can give you one case… And I was in the city. I just took my family, I was in the city so that is the place I work at my house and everything there, so I am in Nairobi and there was a function, a big function. I was to go to attend where I was working so I said okay, I'll go in the evening and the daytime and the evening I'll do that function. I took a bus from Nairobi to where I went in the house, I felt tired, I had a shower, I ate and slept. It was a big party. I forgot about it. At midnight I remembered. And that's what I give..so I know that that's a lapse but I didn't know it was

that. I said, what's happening but I know it mixes me up and I've talked to other people are positive, they say that the memory. I know it does because like my number here, my membership, I can say it, sometimes I can mix some numbers and they know, I told them. Okay, check in that's my name."

b) Initiation of treatment in the U.S.

Eight of the participants were initiated on ARV medications in the U.S. They were started on ARV medications due to the various symptoms encountered. For example, two participants described similar symptoms that prompted the medical team to start ARV medications. In both cases, the participants presented with seizures that needed treatment. Taking the prescribed ARV treatment helped the participants to become seizure free. In the quotes below the participants showed the initiation of therapy and how vital it was to take it.

"I was getting sick every now and then, these three- being I was in and out of the hospital, and then I started having seizures. I went down, I had a seizure right, somebody met me there. I broke my wrist. But then, I started taking my medication, they wanted me to take it. And then I started feeling real better. Until recently, I started having some breathing problems, but I've been much, much better because I take my- my medication as prescribed." (Participant # 3, Female)

Participant # 11 also described the benefits that manifested through lack of seizures after taking ARV medications. He says:

"Experiencing symptoms from the seizures to uh I guess passing out. I guess from passing out is when I was really diagnosed and when I was in- I guess I went to the hospital then that's when they diagnosed me found out what was wrong with me what was like what- why I was having those seizures and why I fainted…"I might not be cured but you know it's working, I'm living I'm not like having seizures every day or getting sick every day or anything like that…"

Another participant was started on medications due to other symptoms he experienced. He explained the issues he had with one of the kidneys that resulted in treatment for HIV as well. He comments:

"I start right away about…at the time I commence, I think my doctor didn't believe that …they embarrass it has been in my system for a long time and it have an effect on my kidney okay? So my kidney was like half…you know, half way so…..so but then I started...they put me on a lot of …several…different medications and as time progress…So but then my kidneys, you know, my kidneys was in bad shape then I started, you know, going to see a kidney doctor and stuff like that. So in 2016, my kidney finally fail." (Participant # 12, Male)

One similar aspect perceived in the narratives regardless of the country where treatment was started the primary motivator for taking medications was “to be alive. “This vision of being alive becomes a motivator for them to take medications. *“I remember to take it because important in my life. I remember to take it because I like it…I like to stay.”* (Participant # 1, Female)

Participant # 11 acknowledges the importance of taking ARV medications. His comparison to a “survival” process gives a sense of the vital role played by the medications in his life. This quotation presents the practical value of taking the ARV treatment that helped him to exist.

> *“I guess it was something I had to do just in order to I would say survive almost like- I thought of it like drinking food and water. Like useful and necessary things for me to do like survive to live and I just- I just added that into my survival needs in my live.”* (Participant # 11, Male)

Participant # 2 depicts the process of taking ARV medications that control the virus level. She pointed out the vital role-played medications in the systemic effect on the virus level.

> *“I’m taking it just to control the whole…whatever. That’s why I take it. Controlling the virus.”*

Similarly, another participant expressed the importance of taking medications through the virus levels and CD4 counts.

"Because my numbers you know changing but I don't know how to describe it. My numbers great!" (Participant # 8, Male)

For Participant # 14 the initial ARV regimen represented a "pill burden." In this excerpt, the participant uses repetitively the terms "three times a day" that emphasizes the initial burden for his daily life. Even though the participant faced a pill burden, he continued to take the ARV medications. However, over time, the regimen decreased.

"…eah. I start with, uh, six medications, six pills. At that time. I take that three times a day…yeah, three times a day. And after a few years that changed and became three pills. And, about four or five years ago it became one pill. Which is [Name] that I'm taking today." (Participant # 14, Male)

On the contrary, for Participant # 8 the "pill burden" was not due to the ARV medications he was taking. This participant feels overwhelmed by a large number of other medications that were prescribed for him. In his narrative, he mentioned taking a total of 28 medications and only one belonging to the ARV regimen.

" …28 pills a day. Five times insulin- and only one is for-And only one is for HIV." (Participant # 8, Male)

Two of the participants who were initiated on ARV therapy in the U.S. also stated that the tablets were larger in size which was inconvenient to swallow. For Participant # 1 mentioned the uncomfortable large size of the medication she was

prescribed. In the second example, the participant also mentioned the inconvenience of the size. Although both participants encountered this inconvenience, they did not stop taking the ARV medications. The excerpts below present this inconvenience:

> *"When I was start I was like it was big because my country we used to small medication anything but here, this country, whenever any medication is big, you know, I was using one medication for coffee is big. In my country I explain like this is big. Is fine. Just I know…whatever is big but it make me to stay…"* (Participant # 1, Female)

> *"I think size is big… but I do not taste them because I take it with you food…I eat food… I do not taste anything… but size is big…"* (Participant # 5, Female)

Accepting the initiation of ARV therapy represented a challenge for a participant. She initially preferred to receive natural remedies instead of ARV therapy. After discussions with her physician who explained the vital role of ARV medication, she was initiated on ARV therapy. During the interview, this participant mentioned that she still takes the same tablet since she was started on ARV. Participant # 2 elaborates:

> "*And so much…so much we talked and talked and said don't worry, we will take care of you. I said, well, taking care of me I know but the thing is, this is not good. But I don't know, so he was my doctor from ….1996…yes.*

That's when…96-97, that's when I was …and he said we will give you the medications and I said..I refused. I didn't want. It took time for me to be on medication. Natural things and all that kind of thing, but finally he put me…the doctor put me on the medication. The first medication I took was [Name]"

As seen in the previous group of participants who were started on treatment in Africa, there were no common side-effects emerged from the interviews. Most of the participants from this group mentioned various side-effects that occurred mainly at earlier stages of therapy. The examples presented below indicate the variety of the side-effects experienced by the participants.

One side-effect described by a participant was the presence of vivid visions. The participant addressed this issue with her physician who recommended to take the medications with food and before going to bed. After making these adjustments, she did not experience these visions. Participant # 3 elaborates:

" Like, I started I left it because of the side effect. When I took it, I used to see like- I used to hallucinate. I'm seeing people coming, people coming with no legs. The first time I used to take it. But then, then the doctor told me, make sure especially at night, when you take it, when you take it, do not eat after you take at night. So, I started doing that and then, the hallucinations stopped, and now I have no problem taking it."

Two participants as a side-effect experienced nausea. When asked if they continued the treatment, both participants responded affirmatively. One participant addressed this side-effect with her physician who recommended to take these medications with food. In the text below the participant described this side-effect.

"I got nausea and dizziness… I went back to the hospital and told them the side-effect... they told me how to take it and what food to take it because of the dizziness and nausea…" (Participant # 5, Female)

On the contrary, the other participant who also experienced nausea was not certain if the side-effect could be attributed to the ARV medications or not. He mentioned experiencing mainly nausea when he did not have food for a while. Participant # 11 elaborates:

"I don't know if this is a side effect. But, I did felt nausea when I'm hungry. Only when I'm hungry, that was like back when I was like middle school or high school. I used to feel like that. I don't know if it's from medicine or not. But that's the only time I ever felt when medicine- I don't know if was the medicine that was affecting me but yeah, I did used to feel nausea whenever I, even if I'm thirsty or hungry I used to feel nausea quickly."

Another participant described vomiting as a different side-effect that prompted to change the time of taking the ARV medication.

"I eat you know, I love to eat, and then I eat but I don't want to take it in the morning, because I drink coffee. Gives me some kind of effect, because I'm

a coffee person. But ever since I start working, you know, I have some kind of experience like feeling throw up and stuff, I suffer… I don't know why, when I drink coffee I throw up. So, for that reason I start taking before I go to bed."

Participant # 14 complained about many bowel movements at the start of ARV medications. Despite being uncomfortable with the side-effect, he continued the prescribed ARV medications and accepted to take additional medication to solve this issue. He tells:

" And that gave me a lot of diarrhea and um… Mhmm. It's what I notice. Because at that time they gave me medication to stop the diarrhea. Yeah. So, I keep using the medication for the HIV and also the medication for the diarrhea too."

This theme illustrated the main reason for taking medications was to remain alive and share a normal life with their families and friends. The next theme will discuss the participants' perceived barriers and facilitators in taking the prescribed ARV regimens.

Theme 7: Barriers and Facilitators in taking ARV medications

This theme describes the factors which promote or inhibit adherence to ARV medications in the interviewed participants. Similarly, to the previous theme were the participants took medications to remain alive, the primary purpose for being

adherent to the pills was to continue their lives. The current theme consists of the participants' statements on how they dealt with situations when they did not take their ARV medications. When participants were asked about their daily routine and what factors contribute to remembering to take medications, most of them mentioned the pills were part of their lives. This theme also presents the dynamics of insurance and the economic factors that contributed to their non-adherence. Finally, this section is divided into three sub-themes: a) Facilitators that promote adherence and b) Perceived barriers to adherence c) Dynamics of Insurance

a) Factors that promote adherence

The initiation of treatment that might have included taking a large number of medications was presented in the previous theme. Since many participants have been taking ARV medications for over two decades, being adherent to the medication became second nature for them. Despite the fact taking ARV medications became second nature for them, some of the participants still use various tools such as pillbox or alarm to ensure they are adherent to the prescribed regimen.

The interviews with the participants showed the emergence of various tools that helped them to remember taking the medications. To illustrate, in the cases presented below each participant stressed out the role played by different adherence tools including pillbox, blister packs, singing alarm, and phone alarm.

For example, one of the participants initially received a singing alarm that helped her to be adherent not only to the ARV medicines; but also, to other prescribed medications. Over time, the participant switched to a pharmacy that delivers blister packs that ensure she does not miss any medicines. The participant says:

> *"…So, they'll give me, uh, something to remind me. That used to sing: "It's time to take your pills. Time to take pills." That was- when I started new- and then he {clinical pharmacist} give me this, the pill box, boxes. This- I mean, the days before I used to take my meds three times a day- well, not the HIV, it's just two times a day. So, all the hours are there to take it {blister pack} … Everything, yea. So that's- that's how I remember. So if I look here, like, today, I will know I have not taken it, then I take it. "(Participant # 3, Female)*

Another participant also talked about the importance of using a pill box that reminded him to take the medications. He carries the pillbox to work to ensure he is taking the prescribed medicines.

> *"Yea, yea. I use the pillbox to get my medication with it. Like, I'm working at night, and I have to take my medication to work, so that I will take it there."* (Participant # 4, Male)

The pillbox has been proved to be an excellent adherence tool for many interviewed participants. It helps them to remember taking the medicines. One participant forgot to take some doses when he was started on the ARV regimen.

Once he started using the pillbox, he did not miss the medication. Having a pillbox helped this participant to achieve adherence. He states:

> *"I used to {miss}! But not anymore. When I miss it, you know I get other stuff, and just miss it and I get sick, cold cough and any other thing. So, {Pillbox} for seven days. I set it up. That's why I don't miss it Monday, Tuesday morning, or in the evening."* (Participant # 8, Male)

Similarly, Participant # 12 also focused on the importance of the pillbox in helping him to take the medications. Initially, it was problematic for him to remember taking the medications. Using a pillbox eased the process of remembering.

> *"Yes. I had difficulty remembering them and the thing is when I start initially, I have to, you know, look at the pill box to know how…but later on I got used to it. I got, you know, I got a box from the pharmacist where I can put how many per days, like 2, 3…"* (Participant # 12, Male)

Remembering to take the prescribed medications presented a challenge to another participant initially. The pillbox helped him to develop a routine. These days he takes the medicines without using the pillbox as a reminder.

> *"Um- First of all at the beginning it was very hard. Because I'm not used to taking medications and sometimes I forget to take medications. And I remember they gave me one of these-{pillbox}. Yeah, so I put all the pills in the boxes to remember better. After a few years it become almost a part of*

me. You know? A habit. It's automatic. Yeah, nobody need to remind me or stuff like that. So, I don't miss my pills." (Participant # 14, Male)

An alarm including a phone or watch was another adherence tool that has been used by one participant. The main scope of the bell was to remind her to take the medications. Similarly, to the previous participant who does not depend on the pillbox, this participant does not use the alarm these days as a reminder. Both participants do not need a reminder tool to be adherent to their medications.

"I used to have my alarm on my phone that, by exactly 10 minutes to 10 the alarm would sound but then not anymore because once you're used to doing something it becomes a routine so, definitely when it reaches that 10 I already know it's time for me to take my medication." (Participant # 9, Female)

On the contrary, one participant still depends on the alarm to take the medications. Initially, she used to rely on her sister's phone call to remind her to take the medicines. These days, she uses the alarm that is an excellent tool to ensure that she is adherent to the medications. She elaborates:

"Immediately in Kenya, I told my sister, she would ring me, she would remember to take if I had forgot it. So, I take at 7 and 7 so she'll call me. She'll refresh to take if I'd forgotten…That's what I used to do but later I started putting my own alarm." (Participant # 13, Female)

To ensure they are adherent to the ARV medications a few participants are using multiple tools. For example, one participant not only uses a pillbox; but also, does she rely on an alarm. In the quote below she explains how both tools helped her to be adherent and take the medicines at the same time every day.

> *"First of all, I have my alarm and then I have the bill box that, you know, I put them like every day. Every day so that I don't, I don't like forget. But I have an alarm, I have an alarm. Always, everywhere I go, I have an alarm. So, my alarm is on you know every time so yeah."* (Participant # 10, Female)

Only one participant discussed the concept of respecting the time of taking ARV medications. For example, the same participant explained why it is vital for her to take the medications at the same time daily. According to her this concept of respecting the time was taught when she started ARV medicines. Later on, this concept was embedded in her memory. It is vital to respect the precise time of taking the medicines because taking them earlier or later will interfere with the pills' metabolism. There is a feeling knowing that she must respect the precise time of taking the medication because this participant perceives it as a part of being healthy.

> *"Because you know, it has, it's stuck in my mind I have to, I have to take my medication. I don't know it- OK, it has never happened – OK then how you were trained, in fact you were told, we were told if you delay like an hour, like today you delay- OK I take my medication at night, maybe I forgot and then I took them at 10, that's an hour late, then tomorrow I delay again,*

maybe 2 hours, those are three hours late, so in a week I have made up- it will total up to a day. Like in my head, if always skip a minute a minute a minute a minute, it adds up, so that's always- that's what has stuck in my mind, that I'm not supposed to skip, let alone a day, I'm not supposed to skip a minute, not even an hour. So, if, if I forget I don't know, It's- I'll go in a panic. (laughs) yeah, I'll go in a panic, I will I will." (Participant # 10, Female)

Although taking ARV medications became a routine for most of the participants, one participant mentioned that he still depends on an alarm to ensure he is adherent to the medicine. In the past, his mother used to remind him to take the medication. However, these days the alarm is an excellent tool to prompt him to take the medicines. The participant says:

"Um, right now I don't really think much when I take it's like a- it's like secondhand now since I was little I've been told to always take it and never miss it and so my mom used to keep nagging at me throughout my whole high school middle-school years and even college she used to nag me to do it. So, I guess like you just take one or two medicines a day so it's not very hard to keep up. I just set up, I start out by just setting up an alarm to remind me to take the medicine and at some point, then it just comes as second nature to you." (Participant # 11, Male)

Another reminder for taking medications was the process of eating. Two participants stated that the food is an excellent tool that keeps them adherent to the ARV medications. For example, in the first case the participant initially used a pillbox. Over time, her habits changed, and she does not depend on a pillbox. Placing the medicine on the table in the vicinity of breakfast prompts her to be adherent to it.

> *"The food reminds me…. When I see food, I know I have to take it. At the beginning I used the box (Monday, Tuesday…etc.) but now I am used to it… when I eat in the morning I have the medication next to the food and take it."* (Participant # 5, Female)

In the second example, the process of eating is prompting the participant to take the medicines. She also emphasizes that the process of taking ARV medications is embedded in her memory. She cannot neglect to take the prescribed medications.

> *"Because, every time I remember, I have to eat. I don't have a {pillbox}, in my bed I have a drawer and that's where I put my medicine. So, in the morning when I take, when I eat, I take my breakfast then I've already taked my medicine. I think, that's something, that's something in my mind like if I don't forget to take my breakfast why I forgot to take my medicine so, yeah, I just take yeah, together because I have to eat something before I leave so. So, I take my medicine, I take pills very serious."* (Participant # 7, Female)

Furthermore, one participant stated that he has been 100% adherent to the ARV medications because he formed a routine in his life related to taking medicines. Eating, the pillbox, and his strong will to live are reminders for this participant. He also emphasized that he has never missed one dose since he was initiated on the ARV regimen. Note how often he uses the verb “forget” in the following reflections. Taking the medication is a daily routine for this participant, and he will not “forget” to take it because he wants to be alive. Both participants mentioned taking the medicines is a process that has been embedded in their minds. He elaborates:

> *“Uh, uh, by the way, the pillbox is around my bed. Before I ate my dinner, I have to remember to wash my hand. Before I wash my hand and go to my dinner, I have to take my pill. This is- I am accustomed to the (Yebra, Holguin, Pillay, & Hue). My body knows, my hand will take the medicine at the right time. My mind orders too. I don’t know why- how it comes, but I’m doing it perfectly. I never forget. How can- how can’t I forget to eat my dinner? How can’t I forget my lunch? How can’t I forget to eat my breakfast? Because it is- because it is my existence, I used to remember these three things. To live, I have to take that medicine, I know…So, even I will not miss a minute. Unless otherwise, I am outside the home, if my pill is there at home, I’ll come- if it passes 50 minutes, an hour, I’ll take the same time. Otherwise, I never miss for a day [emphatically], since I started.”* (Participant # 6, Male)

b) Perceived Barriers to adherence

A few participants discussed some constraints including traveling to another city or staying with a family friend for an evening that could interfere with adherence to the medications. This sub-theme also illustrates how the participants dealt with these situations. Three participants stated that they were not able to adhere to the medication schedules due to some insurance issues.

Traveling to another U.S. town even for a day presented some adherence issues for one participant. The problem for this participant is that he forgot to take the prescribed medications when traveling. When asked how he would take them immediately when returned home, he stated that everything was dependent on time when he was back home.

> *"This is my little problem sometimes, ya know, when I went out, like going to another city. I used to forget, sometime…No, it depend on the time that I get home. Sometime I will come late, like ya know, the time that- let's say I go out of city and come back in the morning. So in that case, I will not take it because yea, it's gonna be too late. You know, the difference between, uh the time I was supposed to and the time that uh, I'm on a, yea. So, yea, sometimes, most of the time I will not take it again. But if I come like, ya know, a difference of less than six hours, I mean less than four hours, I will take it. I will take my medication."* (Participant # 4, Male)

Only one participant talked about forgetting to take medications when he spent the night with a different family member or when his parents were not around to keep reminding him. The participant emphasized these situations occurred when he was not an adolescent. He perhaps forgot to take the medications because he did not understand at that young age the role played by the ARV medications in his life. The participant stated that those situations were in the past. In the quote below the participant describes that situation when he went to stay for a night with a family member and failed to bring his ARV medication.

> *" Oh yeah, it did happen as, like a, this is when I was very young too throughout my teen years, young teens so I did forget to take them even though my parents remind me sometime when they leave and stuff and when I was playing around or sleeping over to my older sisters and uncles place and when I used to go and I'd forget to bring one with me. So, times like those I did forget…Yeah I'd forget to take some in those moments when I was still young and inexperienced and so then I wasn't still for sure focused on what my issue and disease was."* (Participant # 11, Male)

Failing to refill the pillbox impeded one participant. However, the participant realized the issue and fixed it immediately. Not only does she talk about this problem that occurred only once; but also, she emphasizes the solution. Clearly, this participant is aware of the negative effects if she forgets to take the medications.

“ What happened to me one time, it’s not like to forget my medication, I always pack them in my med purse so that container only carries 10- 8 pills and then the rest I leave in the house so I walk with that purse everywhere I go but, one time I went to school and from school I was going to work and I forgot to refill my purse so I left- on my way to work I realized I don’t have my medication to take. Then I had to turn around and come back to the house to get the pill because I’m like, I’d rather be late for work but not miss my medication, not for anything, I wouldn’t want to miss my medication.” (Participant # 9, Female)

Adherence to the medication regimen was a problematic issue for Participant # 14. Once the time passed, taking the pills became second nature for him. When asked how to deal with the effect of the missed doses medications, he stated that per physician recommendations he would not double up the medications and will continue taking the remaining of the doses. In the following quote, he explained how he dealt with missed medications.

” Uh, I remember the doctor told me, doctor [NAME], told me when you miss one don’t take two the next time. So, when you miss you miss. I don’t take- I don’t double because I miss the last one. Well, yeah that is long time ago I didn’t miss any pill at all.” (Participant # 14, Male)

A few participants reported insurance issues to be an essential obstacle for being adherent to the medication regimens. For Participant # 4 the change in the

insurance at the beginning of the year prevented him from taking the prescribed ARV medications. According to his narrative, the pharmacy was not aware of these insurance changes that impeded the participant to take the medications for nearly a week. Fortunately, he was able to solve the issue by calling the case manager, and the insurance was reinstated. He further elaborates on this issue that occurred a few times recently.

> *"Yes, there's a time that I went to pick up the medication, they asked me for, I think it was $15. And that time, I don't have $15, I have to come back without taking my pill. That is the first time, I say- no it's not, it's not only that. Uh, it was this year, I stayed like, more than four days without taking my medication. It happened that when I switched the- the insurance. Ya know, the insurance they have on a file when they try to go through the insurance was not active, and they didn't give me the medication. And I- I already ran out of medication. And I have to call my case worker and a colleague, and the last time when I called them, they didn't answer me on time. And I have to stay, ya know, without my medication because I don't know the insurance- I mean, the number- the ID numbers of insurance to give to the department so that I will get my medication on time. And that one it took a while and I'd say like almost four to five days without medication."* (Participant # 4, Male)

Unfortunately, in the following example, the participant was not able to solve the insurance issue very quickly. He was expelled due to some errors from the

subsidized government insurance plan. Not having insurance coverage resulted in not receiving his necessary medication regimen. Consequently, this participant did not take his medications for nearly six months. Failing to take the prescribed medications for almost six months had adverse effects on his health. The CD4 counts decreased, the viral load raised, and he was more susceptible to opportunistic infections. Furthermore, the raised viral load means it was not undetectable, and he could transmit the disease. In the quote below the participant discusses how this insurance lapse affected his life.

> *"Yes. At one point my medication was caught up, I mean, my insurance was caught up, I mean the insurance got a whole lot of irregularities. You've got to submit papers, you've got to submit your income and every 6-months you've got to renew it and when you miss any kind of little error, you know, they right away call you up and so forth like that. They called me up, you go to [Name], they have to give you something like a temporary med which is half of a month, until your papers goes through… At one point I was out of medication for almost like 6 months. Why? The papers were not going through and then they put be back on and like that, when you're out of medications the viral level increase and you got sick and you get back in the hospital again so. I went back on the insurance and then got back on my regiment and it's like you've got to start all over again because you've got to take the kind of amount of medications to bring your viral levels to the last stage that you were before. Yes. I mean it's like you…it's like you being*

diagnosed again. Because the virus is…once you're off the medications, the virus rebuilds." (Participant # 12, Male)

In the third example, again due to some insurance issues the participant did not take the prescribed ARV medications for a few days. The participant talked to the case manager who called the insurance and solved the problem. In the quote below the participant says that the insurance problem was the main reason for not receiving the medications.

"I do not forget to take…but one day I went to the pharmacy and the insurance did not work… so I did not take for 5 days … I called the case manager." (Participant # 5, Female)

Theme 8: Accessing the U.S. healthcare system

This theme presents the participants' perspective of the U.S. healthcare system and how they learned to navigate the system regardless they were diagnosed with the disease. When asked how they paid for the medications all the participants stated they had a form of insurance at the time of the interview. Most of the participants also answered this question by providing examples when the case manager helped them to coordinate payment. They also pointed out how vital is to have a type of insurance that permits access to the U.S. healthcare. Not only does the insurance enable them to access the treatment and physicians; but also, does affect their lifespan. In addition, this section portrays the economic factors faced by some participants when dealing with the complex healthcare system.

Some of the participants alluded to the role played by the individual case manager or social worker who helped them to obtain a better understanding of the U.S. healthcare system. All of these participants were brought up in a centralized healthcare system.

Two sub-themes emerged when the participants described their experiences with the U.S. healthcare system. These sub-themes are:

i) The role played by case manager in navigating the U.S. healthcare system
ii) Interaction with the physician
iii) Dynamics of insurance

i) The role played by the case manager in navigating the U.S. healthcare system

This sub-theme describes the role played by the case manager in helping the participants to navigate the U.S. healthcare and easing their way to receive the appropriate care. This sub-theme emerged without prompting the participants. The participants stated that whenever they experienced financial difficulties including paying for medications, needed transportation for a medical appointment or needed a referral, they would contact the case manager who would address those needs. The role of a case manager is to coordinate services that better serve the HIV individual.

Most of the participants talked about the significant role played by case managers in helping them whenever they faced any monetary issues. When asked to describe in what type of circumstances the participants would contact the case

manager, the participants responded mainly related to insurance and financial issues that would interfere with adherence to medications.

The following excerpt indicates that one participant relies on the case manager to direct her problems.

> *" Help me when maybe insurance is no work. Help me to open and to call the people anything happen. Maybe when bill come like already I have medication, but you need more money like it's too tough on me every month but maybe come more. Maybe $6, $18 dollar no have it. Case manager help me to cover that. To call people to help me cover that."* (Participant # 1, Female)

Another participant discusses the role of her case manager in coordinating her transportation whenever she needs it. In order to receive these transportation services, the participant has to be enrolled in a specific Medicaid insurance program. She elaborates:

> *"Anything that you want to do, there's a provision of transportation. You are connected when you are in the program. You have a case manager that you deal with and he's always nice. Whatever we have, you call the one responsible for transportation that I want to get to this place. As long as you give him enough time …been given a day in between if I'm going to the clinic on Friday, I have to call him on Wednesday so that there is a day between to put things together and then Friday then you can go. But where an agency is needed …they can give you transport right away."* (Participant # 2, Female)

In the following example, the participant developed a relationship with his physician who connected him with a social worker. The role of the social worker was to guide the participant further to apply for the most appropriate insurance plan that fulfilled his financial needs. In other words, the social worker helped him to apply for the government insurance that has been paying for his ARV medications. Furthermore, the participant emphasizes the role played by his physician and social worker in advising him and his family to receive the best insurance plan that covered his treatment.

> *"I applied to government insurance. They provide, they pay for it {treatment}. I never would have to struggle I had to my doctor she- my first doctor [Name], she really helped me out and my parents out to connect us with social workers and stuff, so I had the social worker that helped me out through the insurance process and what plans that can help me out. So thankfully I guess I have those people that watch out for me even though they're not really family they're still looking out for me. Through that network I found this insurance which I'm still. So, I never have to worry about financial needs for medicine."* (Participant # 11, Male)

Another participant discussed the circumstances when the co-payment for his daily medications increased in price because he was expelled from the government insurance program. According to his statement, when the situation occurred, he contacted the case manager immediately who solved the issue, and

he could continue his treatment. The following excerpt presents the participant's situation.

> *"Sometimes they cut me off. Yeah! Sometimes I have to pay you know, once a year or two times a year they give me a hard time to get my medication all kinds of medication. So, the social worker and the case manager help me…"* (Participant # 8, Male)

Similarly, to this participant, another participant stated that when she encountered an insurance issue at the beginning of this year, she contacted the case manager who was able to find a solution. Due to the case manager involvement, the participant was able to continue the treatment after missing a few doses.

> "*but one day I went to the pharmacy and the insurance did not work… so I did not take for 5 days … I called the case manager."* (Participant # 5, Female)

ii) Interaction with the physician

This third sub-theme presents the participants' perspective on the interaction with their HIV physician who contributes to their wellbeing. When asked if they have any clarifying questions about their disease or the prescribed medications whom they contact, all of them responded the first communication would be their HIV physician. A few participants mentioned the role of physician in

the difficult moments of their lives such as the diagnosis or the initiation of the medications.

To illustrate, one of the participants stated she communicates with her physician via email or phone whenever she has questions.

> *"I would contact my provider, like I said I have MyChart with me, so I always shoot a message to her in the email and then she would respond, or I would request to talk to her on the phone and make an appointment to go and talk to her."* (Participant # 9, Female)

Establishing a cordial relationship with the physician helped the participant to go through the difficult moments when he received the devastating diagnosis. In the excerpt below the participant mentions the significant role played by the physician in explaining the importance of taking the medications.

> *"And also my doctor too [NAME] at [NAME], I mean, beside he talked to me personally like a father and he encouraged me that, you know, if I take the medications, I can live so and I follow that and I feel that if I follow his advice, I still have continuation of life."* (Participant # 12, Male)

One of the participants initially mentioned the usage of internet for some of the disease-related questions. He further clarified the role of the internet by saying he likes the videos that explain how the virus replicates. In addition, listening to the physician responses and explanations of the roles played by each medication helped this participant to have a better understanding of the ARV medications in the disease stages. Even though the participant has limited biology knowledge, he

enjoys the physician's answers about the medications mechanisms of action that broadens his horizons. At the end of this quote, he reinforces that whenever he would have further questions about his disease state or medication, he would contact his physician.

> *"I would first look online {looking at videos} but then I think I would probably start asking my doctor. I think my doctor, he's very open- He's a one the old age side and he's a very friendly doctor. And he always asks- try to be open, try to tell me what diseases- what each medicine is doing and what each component how it attack and stuff which he explains to me in every meeting I have with him. Yeah, yeah because even the- I am a college student I don't know much about biology. I really like biology but I can somewhat understand from explanation but yeah, I guess it helps me understand I guess probably how I can help others too but sometimes maybe the doctor explains to you what each medicine is doing and you can be like "oh I see" even if- you don't have to fully understand what each medicine is doing but knowing that you can see that it's working. I guess it does help knowing what each medicine does so if I ever have to have a question I think I would just like tell it to my doctor."* (Participant # 11, Male)

Similarly, an additional two participants appreciated a cordial relationship with their physician. In the first example, receiving the physician's recommendations on the prescribed medications is vital for this participant. Not only does the information help this participant to take the prescribed regimen; but

also, does it benefit the wellbeing. In the following excerpt, the participant explains how the physician developed this cordial relationship that enabled the participant to rely on the physician's advice.

> *"Uh, what help me to improve my health is uh, especially that advice- advice from the doctor. Because when I see the doctors, ya know, it will give me more advice on taking the medication, OK? And he will ask me, ya know, "How you been? How your medication going? Are you taking your medication?" And I will tell them what- what I like, what I tell you. Sometime missing the medication, not to take the medication, and all that stuff. So, he will advise me more how to not forget the medication, how to be on the medication and that- like, you know. "(*Participant # 4, Male)

In the second example, the participant presents her cordial relationship with the physicians. The participant explained that she had to talk to two different physicians because the primary one was on motherhood. According to her, she developed a friendly relationship with both physicians. She says:

"I've been meeting very good people. My case managers, my doctors have been very good. I've changed one doctor because she went for maternity leave and I was given another doctor. So, I see this other one. So, I like both of them. When the other one is not there I say, I'll see the other one.... Because I have a good relationship. They treat us well." (Participant # 13, Female)

iii) Dynamics of insurance

This sub-theme describes the participants' experiences with the insurance. All of the participants in this study had insurance at the time of the interview. Despite the fact the participants had insurance, some of them discussed different insurance problems they were confronted with and how the issues were resolved. To solve these insurance issues, a few participants consulted with the case manager or social worker.

In the excerpt below one of the participant presented the financial burden she faced when private insurance covered her. She stated that she was planning to stop taking her ARV treatment because she could not afford to pay for it. This participant noted this financial burden occurred before she enrolled in the Minnesota Medicaid program that covers her ARV treatment. The participant elaborates:

> *" Mm. I mean, when I was diagnosed newly, I was working and I was still on my- my job insurance. But then, by the time they could cut my job insurance, I applied when they had deemed me disabled, I applied for Medicare- Medicare insurance. Yea. Just before I got approval of this, it started getting really rough, but luckily when I got approved, they pay all the- the bills, Medicaid. I mean, when I used to go for my refill, I mean, at one time they told me the HIV was like, $900. And I was wondering, where am I ever going to get that from? So, well as God would have it, I got approved, and they just paid yea, all that was- I was all in the pharmacy, mhm."* (Participant # 3, Female)

In the next examples, a few participants mentioned the co-payments for their ARV treatment is a financial burden for them. In the first case, the participant stated that there were situations when the co-payment was too costly for him because he is unemployed. When asked how he solved the problematic situation, the participant answered the physician's office covered that co-payment. He says:

> *" Oh, I cannot pay for my medication, but state is paying- Minnesota state, I think. There is a co-payment, $3. Around that. Yea, uh, sometimes. Anybody who knows because I do not have any job know. They- they can give me, for tele- telephone, for a post, 20, $10. If it is in my pocket, I'll pay, otherwise my doctor will pay."* (Participant # 6, Male)

The co-payment for treatment represented a financial burden for another participant. When asked how she coped with the co-payment, she borrowed the money from a family member.

> *"I have a co-pay … $6-$7… I have insurance. There was a time when I asked my daughter to give me some money to pay for it."* (Participant # 5, Female)

In the last case, another participant seemed to face difficulty in paying the co-payments for medications. Per the discussion, this financial burden occurred a few months ago, and as a result of this issue, he interrupted the treatment for a few days.

"Now the government pay for it, not me. The government cover everything. I just pay sometime the- the co-fee? Yea, the co-pay, that- that is sometimes, I use to pay. Like when I go to pick up my medication. Sometimes they charge for $16, it depend on the medication I'm taking. Uh, 16, 10, $15, they'll charge me for that…I think it was $15. And that time, I don't have $15, I have to come back without taking my pill." (Participant # 4, Male)

A delay in the approval of a participant's insurance resulted in not taking the prescribed medications. Even though the medical team was aware of the delay, they could only offer a limited amount of medications such as for two weeks per visit. The participant did not take the ARV treatment for nearly six months. In the quote below he explains how the delay in his insurance approval affected his life.

"Yes, he knew what was going on and even though they give me two weeks...and I was going there and they were searching the papers and we were waiting for the health department to approve of it. Yeah, so, that was it but I was going….and every morning I go and see my viral levels going up. What they could do is just give me something like 2 weeks. And then when your viral levels go up like that, you don't need two weeks medication, you need constant medication to suppress the virus." (Participant # 12, Male)

On the contrary, a few participants stated that the insurance plan covers their ARV medications and they did not encounter any issues. Due to the insurance coverage, in the first example, the participant did not have to pay for her treatment. When asked if she faced any financial burdens in the past, she denied this. The participant explains further about her insurance coverage:

> *"I don't pay for medication, yes. Yeah, I don't. I just- [NAME] introduced me to where she goes, the clinics so, I take my medication every month. No, no, no, no. Anytime I'm sick I just go, they give me medication. I don't, I don't pay for any single medication."* (Participant # 10, Female)

In the second example, the participant is using two different insurance plans to pay for his treatment. The participant has a job that enrolled him in their insurance program. In addition, his social worker helped him to apply for the Minnesota insurance program that covers any co-payment left from the primary insurance. Due to these two insurance plans, he can afford the treatment without interruptions.

> *"I have insurance through my work [NAME OF WORKPLACE] I have my insurance through them because I'm union so, insurance pay for the medication. And I- my social worker put me also into a HH program. It's the government stuff. I think the government pay the balance if something's left. The government take care of that. So, I don't pay anything from my pocket."* (Participant # 14, Male)

In the last example, the participant stated that she is enrolled in the Minnesota insurance program through the government plan that covers her treatment. When asked if she encountered any difficulties paying for her ARV medications, the participant denied it. She elaborates:

> *"Right now, I'm covered with the project HH that covers for my medication. No, I have not had that experience, it's just when I started treatment I already had medications from Africa when I came in and then when I started the treatment I was already working so I wanted to get the insurance. Yeah."* (Participant # 9, Female)

The same participant stated that one of the Medicaid insurance limitations is the lack of opportunity to receive ARV medications for more than a month. She is the only participant who mentioned this limitation that prevents her from traveling to outside of the U.S. According to this participant if she wanted to go overseas for more than a month then she would not have enough medications supply to continue her treatment. One solution provided by the participant is to have a friend who could pick up her medications and send it via the post office. However, this solution has another problem that is the high price of posting. She further elaborates:

> *"Hmm, what I like about the, like I said the medication in Africa was generic medication and we used to be given medications for up to three months to use, so the difference here we only get medications for a month. But I came to understand it's because the medications are expensive, and the*

insurance has to be billing them every month. So, it was a lot easier when you have medications for three months, even if you had to go someplace you'd comfortably stay there for three months and when your day comes for your appointment you come back and pick up your medication. But unlike here, even if I have to go to Africa I will only get medications for one month so I have restrictions, so I have to stay in Africa for a month or I have to have somebody to pick up the medications and send them to me in Africa from the extra period of time that I'm going to be there. And sending medications to Africa is very expensive… Very expensive, I sent, my husband left here he came to visit and went back to Africa and he was going to stay there for just a month and a half so the medications he had were for one month. And so, the extra fourteen he needed medication, so I had to take the medication and send I spent 140 dollars to send the medication. Yeah, so even imagine if he has to stay for six months meaning you will be spending 140 times six. It's nearly $ 800. Which is a lot of money." (Participant # 9, Female)

Theme 9: Role of Herbal Remedies in Their Treatment

Under this theme, one of the research aims of this study is answered by understanding the participants' perspective of the role played by alternative medicine including herbal remedies in their wellbeing. When asked about their

wellbeing and the usage of herbals, teas, exercise the participants responses are divided into two groups.

In the first group, some of the participants stated they use various herbal remedies or teas. In addition, a few participants mentioned they had faith in the herbal remedies or in “natural healers” and had used different natural therapies in the past for minor illnesses.

In the second group, a few participants stated they do not use any herbal therapies. When asked for the reason, they did not elaborate further. However, a few participants who do not use any herbal remedies explained the lack of usage.

The participants’ statements shown below reflect their knowledge and perspective about the usage of natural remedies. A few participants explained the significant role played by herbal remedies in their country of origin culture. They also clarified why some African people would rely solely on the usage of herbal remedies for their treatment.

Participant # 10 described her country of origin culture and their perspective on natural remedies. To better understand her original culture, she provided examples of why their culture relies on natural cures for many diseases. Furthermore, the participant emphasized that certain disease states cannot use herbal remedies. Note how often she uses the word “herbs” in her statement. It is evident that the “herbs” are ubiquitous on the African continent and some participants demonstrated deep awareness. When asked if she ever used these types of remedies, she responded affirmatively; however, the usage occurred only for minor illnesses, and it was in the past.

"You know, you grew up with grandmother, you know you are sick, your head aches, there's something that is grind and then, mixed with either milk or something or soup you know, the- bone soup. They boil the bone soup and there's a medication that is grounded and then mixed that you're given and then you're healed. I don't know how but you get better. You have a stomach ache there are certain, bark or a tree or a root or a leaf that is grounded and then mixed with either you know, the soup or the milk or whatever it is. Then you give it. You have a wound you know there's something that is grounded, you know, mixed with Vaseline or something and then they apply it to you and so, it was it was, the majority is just herbs, herbs, herbs here, herbs there, herbs here, herbs there and so- you know, you know, and then every we have some tribes yeah? So, this some tribe they are well known for this kind of- of illness, there's this tribe you know, and so, people would be moving from here to there, to there, to there to there because they heard in this county or this village there's this man who treats this. And so, they would go and like that. So yeah, I think the herbal {market} back at home is big. It's big. Like people have grown with the herbs. They are there and, OK some work, some work I've seen some work. Like you have wound, there's something you're given and it heals. You know, you have a headache like that. But now the major all the big, illnesses like maybe Malaria, you know, you can't go and get a herb for Malaria. Even if it's the healing the part, maybe it just suppresses, but it's still there. You know, HIV, there's no way you would- it's- it's- even the doctors themselves

they've not found the treatment. Now how would you just come up and say, "I have a herb that treats HIV completely." (Participant # 10, Female)

In addition, the same participant also discussed the controversial usage of natural remedies by the most affluent HIV people. In order to better explain this controversy, she provided an example that was popular in her time and used by many people. Her usage of the term "what" emphasizes her disapproval of trusting the herbal usage. It was evident that relying on the natural remedies did not save the lives of those who could afford to pay exorbitant sums for those dubious treatments.

"First morning- the first urine in the morning, you take that a glass and the herbal. And then you drink. So, it cleanses you according to them. It cleanses you and with time your HIV will be gone. I'm thinking "Whaaat!?" Yeah, so, yeah, herbal is big. Then- I don't know if it's still there, but when HIV had just come in, oh yes, they made so much money. The rich really went and they also died. They also died, so poor us we didn't have that money to go for the herbal we managed to survive." (Participant # 10, Female)

Similarly, another participant reinforced what the above statements explained. Besides, this participant used the expression "traditional healers" that was not used in any other interview. He elucidated the reason why some African people rely more on "traditional healers" rather on physicians and Western

medicine. When asked to further elaborate on the meaning and the role of "traditional healers," the participant stated that there are strong beliefs that various diseases are caused by malicious souls and could be cured by the "traditional healers." He says:

> *Uh- (thinks) Yes. Yes, because when you are growing up, when you are sick, they don't take you to the hospital. They put together some herbs, like those- they know that, they put that together and it's a potion, they boil it and you drink it sometimes you are, yeah you are healed. Yeah, you are healed. And also, there are we call them [tragie de la peut French word] they are traditional healer. Yeah, they are like doctors. They know some herbs to heal a lot of cuts or- any kind of sickness. They know that. That is why in some African country today some African countries they are calling those traditional healers to the hospitals. Yes! Yeah, when the doctors cannot- cannot heal some sickness because they think that it's coming from a bad spirit, they call the traditional healers and they take care of the situation. Sometimes that works. Mhmm."* (Participant # 14, Male)

Although the same participant said he sometimes believes in the miraculous powers of the "traditional healers," he pointed out the lack of scientific evidence for the herbal treatment. When asked if he used any herbals or "traditional healers," he stated that his parents gave him various herbal remedies when he was young for some minor illnesses and denied using "traditional healers." Furthermore, he

emphasized that he has not utilized any herbal remedies since he was diagnosed with HIV.

> *"Oh yeah. That works. Sometimes. But the thing is they don't have means to gauge you know, in any medication you have uh -an amount- amount of element in the medication. The traditional people they don't have any way to measure the herbals elements. Sometimes it's too much, sometimes it's not enough but they follow the patient and sometimes they heal."* (Participant # 14, Male)

As seen in the statement below, one participant is taking a supplement medication because his physician recommended it. The role of that supplement medicine is to eliminate an element from the diet.

> *"Yes. I take something. It's prescribed by the kidney doctor. Yeah. It's a supplement. It's there to remove the potassiums from the food."* (Participant # 12, Male)

A few participants stated that they take some herbal remedies because they believe in these medicines' powers including alleviate the pain or enhance the strength. To illustrate, in the first case the participant described and provided detailed examples of what she is using and how she prepares them. She obtains most of the information about these herbals from various magazines. This participant is the only one who provided comprehensive information about the herbal remedies used. Note in the excerpt below how through she presents the

information about her herbal remedies. At the end of the statement, she questioned if these herbal mixtures might affect her blood pressure.

> *"I've had so many problems but also I do healthy, I do turmeric, I do ginger…I do other things. I read about those so they help me. Now I don't have so much problems. Yeah. In the morning. Most mornings {Ginger}. Sometimes just days I've started having a lot of pain, which I did not come for…I come for acupuncture I come for chiropractic but I'm experiencing a little bit of pain some days and I wake up in the morning and I take a big mug like 2..those 2 bottles of water because I don't like cold, I warm it a little bit, I just warm but I boil a bit of it, I put ginger in, I put sometimes I put garlic but I don't do garlic so much because it taints the blood and all that so I do turmeric, I put ginger, I put lemon and then sometimes honey a little bit not to take too much. I take those in the morning. Sometimes I do lemon. After that…at first, I do water, I can even do free water when I wake up I take lemon, a full lemon, I cut it and brand it, I take it whole like that with seeds and everything to clean my kidney and clean my liver. Every time, I do smoothies for like chard and…I do like spinach, I do carrot I do celery…many things. Yeah. Beet root…my blood goes down all the time I don't know why."* (Participant # 13, Female)

In the second example, the participant mentioned the usage of only one herbal supplement because she believes in its enhancing properties.

"Yes. It's a natural product called Meringa. Yes. That he say it heals so many kind of ailments. Is a kind of a supplement. Because they say it boosts the …what… what is that…Immunity… (Participant # 2, Female)

In the last examples, the participants stated the usage of herbal teas. For Participant # 7 mentions her traditions of drinking herbal teas. She revealed that whenever she travels to her country of origin, she would bring herbal teas to drink.

" Oh yeah, we have a Kenya tea, like uh, we drink Kenya tea and yeah we have a tea like every time when I go Kenya I bring yeah, and I brought all the spice from Kenya so tea, coffee from Kenya, yeah." (Participant # 7, Female)

Similarly, another participant stated the usage of herbal tea because he enjoys drinking it and believes in its calming properties.

" I love tea. I drink tea. I make my own. Cinnamon. I buy cinnamon and uh coffee uh- what they call it- grounds? And then I make my own. Makes me relax." (Participant # 8, Male)

On the contrary, the second part of this theme presents the participants' statements who do not use any herbal remedies. Although all participants were born and raised in Africa where the culture is more prone to use herbal remedies, one participant stated that they do not believe in herbal therapies. As seen in the statement below, not only does the participant not have faith in herbal medicines;

but also, her family did not use them either. According to her statement, she trusts God and physicians rather than herbal remedies.

"Yea. I didn't come from that family [as in: that type of family or system of beliefs]. We go to church, we just pray. We go to hospital when we get sick. Yea. I never saw my mom herbal or pray to other things to get rid to you. To take, no [take it away]." (Participant # 3, Female)

Another participant said she is not using any herbal remedies. One explanation she offered was the lack of transportation to go to an African store.

"No, no {herbal}. I'm not really go African market a lot because I not drive and sometimes I'll just go Walmart or Cub Food and that's my store." (Participant # 1, Female)

Similarly, some participants stated they do not take any herbal therapies. When asked to elaborate further, they did not provide any explanation.

"No, no, no. There's none." (Participant # 4, Male)

"No, I don't take herbal." (Participant # 5, Female)

"No, I don't take any herbals, or remedies." (Participant # 9, Female)

One participant mentioned he did not use any herbal remedies; however, he used to take Vitamin D that was recommended by his physician. As seen in the following excerpt, the participant described how he used to be more active in the past and how he will seek more physical exercises shortly.

" No. I did- I did use vitamin D I guess my doctors tell me I need more vitamin D since in my country there's a lot more sun there than here. So we usually get more vitamin D from back home. But yeah. Beside that uh, I did exercise for three or four months and I stopped because of school and work since I work at school at the same time. I kind a stopped working out but physically uh I do like to play soccer a lot too, so I try to play soccer as much as I can. And I was hoping to start working out soon for spring break too, but we'll see how that goes." (Participant # 11, Male)

Theme 10: Interaction with pharmacists

This theme describes the participants' perceptions of pharmacist roles in their treatment. The study participants used terms such as "nice," "good," "business" to characterize their interaction with the pharmacist. When asked to explain the settings of their interaction with the pharmacist it was clarified that the pharmacist could be in retail, outpatient, or a clinical setting. A few of the participants receive their ARV medications via mail order, and according to their statements, there was limited interaction with the pharmacist. Overall the perspectives of participants of the role of pharmacists in their treatments are more of a "transactional nature."

When asked if they would disclose the HIV positive status to a pharmacist, in case they needed to purchase an Over-the-Counter (OTC) from any chain

pharmacy, then the participants' answers resulted into the emergence of two sub-themes.

a) Revealing the diagnosis to a pharmacist

b) Lack of disclosure of the status

The following quotations indicate a "transactional" relationship between the participant and the pharmacist. In the first case, the participant describes the relations with the pharmacist as being "good" because the pharmacist counsels her on the prescribed ARV medications.

> *"A good one. When I visit, they give me the new medication. She {the pharmacist} explains to me how to take it and sometimes what will happen and so forth so…we are in good books with my pharmacist. Good relationship."* (Participant # 1, Female)

In the second example, the term "nice" was used by a participant to characterize the relationship with the mail order pharmacist and the pharmacy staff. When asked to elaborate the meaning of "nice" relationship, the participant explained that the pharmacist asks her additional questions to better determine if any changes that have to be addressed.

> *"Oh yea, they are very nice to me. The lady at, uh, [PHARMACY], she's- she's nice. She calls me, asks me how I'm doing, how are my meds doing. Even the driver that brings- deliver it, he's a nice guy. Mhm."* (Participant # 3, Female)

In the third example, the participant reinforced the “transaction” part of the relations where he perceived that the relationship presents similarities regardless of which pharmacy he fills his ARV medications. He also stated that the “payment” for medications plays an important role in the “transactional” part of the prescription. In the quote below this participant expressed his personal view of the “transactional” relationship with the pharmacist.

> *“I think- there’s no different as long as you pay your, ya know, the fee that they want you so they will give you the medication. So, the thing, ya know- when I used to pick it from- So when I go there, ya know, they will- first of all, I will call them and order the medication to refill. So they will refill it and when I go there to pick it up, I will go and pick it up and so. It is depend- if I have the money, the fee that they wanted, I will pay the fee and then they will give me the medication, so there is no problem.”* (Participant # 4, Male)

Furthermore, another participant used the term “business communication” to illustrate the relationship with the pharmacist. The participant also emphasized that the lack of a caring relationship between him and the pharmacist. He made a comparison between the physician and the patient relationship that is more caring and comforting. In the quotation below, the participant presents his view of “business communication” by pointing out the lack of tone change when the pharmacist talks to him. He further elaborates:

> *“No, no, no, like a doctor like the feeling that you get like a support type of thing. It’s mostly just like mostly business communication. So, it’s not- yeah,*

you won't notice any change in their voice or anything like that. I don't feel anything from them. Just like, "yeah did you order this?" "Yeah, it's fine you can have that." (Participant #11, Male)

Greeting the participant and explaining the effect of medication was perceived as a positive relationship by one participant. However, the participant did not develop further when asked to clarify the role of the pharmacist in her medication regimen.

"Now… I have a connection… every time I go to pick up she {the pharmacist} knows me…and she say "Hi" to me and we talk sometimes about medication." (Participant # 5, Female)

Familiarity with the participant and being a patient at a specific pharmacy for nearly a decade resulted in a cordial relationship. One of the main obstacles described by the participant that might have interfered with this warm relationship was the insurance. Participant # 12 stated the insurance issues were resolved.

"Ah it's not bad. I think just about 10 years ago they know me very well. I open the door and they give me my medications straight. They know me. The only problem can be is I used to have problem with insurance when you miss a little arrow on the paperwork but that has been taken care of now so …so far so good." (Participant # 12, Male)

There were also participants who described a positive relationship perceived through pharmacy services such as providing refills and resolving insurance issues rather than presenting a relationship with the pharmacist. For instance, Participant # 6 states that he has a good relationship with the pharmacist because of the services they perform including replenishment of his ARV medications. However, the participant did not clarify further if the pharmacist played a role in the treatment he received.

> *"Yea, yea. I used to talk with them by telephone. Eh, I tell them to re- I want to refill my medicine. You make it ready for me, I take it on this day. They do and I go and pick [it up] with my family."* (Participant # 6, Male)

Another participant presented the role played by the pharmacist in having a medication covered by insurance. Note how the participant considers the relationship with the pharmacist as not being "a special one." However, she emphasizes the pharmacy staff was paying attention to her concerns. She says:

> *"Not really special, but they are very kind and they have all the time to listen to you whatever issues you have. Because I remember there was one time, there's this skin infection that I have that always comes on and off over on my scalp so, my insurance was not covering for the medication for that but at least the managed to maneuver and tell you that there's a smaller medication that your insurance would cover that contains the same combination that this medication has, this one is just a little expensive that's*

why your insurance cannot cover but then if you take this one it will act the same. So, yeah." (Participant # 9, Female)

Having the medications mailed to a participant's home is another service offered by the pharmacy. This participant does not use mail order pharmacy. On the contrary, she uses a retail pharmacy. However, due to the lack of transportation, the pharmacy has to mail her ARV medications.

"I like them, they are good. Like now I get the medication, I don't pick it because I don't have a car and I don't want it to come this way where I walk so it's in Minneapolis. I don't pick it so they post it to me." (Participant # 13, Female)

The same participant also described the counseling she receives from the pharmacist whenever she goes to the clinic. The advice offered by the pharmacist assists her in taking the medication regimens correctly. She comments:

"Yeah, they are very helpful. They also ask me which medication I am taking. They tell me this medication you take this and this…you have to take before you eat, after with food….things like….like that, I mean, before you eat…they always tell me, yeah."

The term "nice" was used again by a different participant who presented his relationship with the retail pharmacist. However, in this case, the participant did

not find beneficial the counseling on the ARV medications because of his familiarity with the information from the clinic. He comments:

> *"Yeah, they are nice, with me anyway. They are nice, they try to explain me more about the medicating but- I know those things already because at the clinic people are- in the clinic they are taking care of me. I know all those things already, but they try to repeat to me. But they're nice. Yeah."* (Participant # 14, Male)

There are only two participants who had an opposite experience rather than "transactional" with the pharmacist. Both experiences occurred in the clinic with the clinical pharmacist where they go for a routine control. In the first example, she described the meeting with her clinical pharmacist who played an essential role in explaining the rationale why she has to separate some of her medications from the ARV ones. In the following quote, she elaborates on this positive experience she had with her clinical pharmacist when advising on her current ARV medications.

> *"Oh, they are good (laughs) they are good, very good, very good. Yeah, they would also advise like what to- OK, they are- in fact before then I didn't know, like when you're taking HIV medication, shouldn't mix with any other medication. Yeah? I didn't know. I would take, like if they've given me, like if I have HIV- my, my, my normal medication and then I have maybe something else. Maybe like the calcium, the vitamin, I would put them together and take them together at a go. So, this pharmacist told me "no, no, no. You have two HIV medicine, you take them on their own." On their own, yeah. So, I if I have any other medication then I take them um, maybe*

an hour or two after. Yeah, but HIV medication, take them singly, just like that. For them to work better." (Participant # 10, Female)

In the second example, the participant presented the role of a clinical pharmacist who meets with him quarterly to discuss the medication regimen. As can be seen in the quotation below the clinical pharmacist plays an essential role in his medication regimen by making any changes needed.

"Yes, like {Clinic Name} has a pharmacist…they look at my medications and they see on my lab test, they want to take out some medication I will go and meet and then they will explain to me you don't need to take this other one. We're replacing it with this or stuff like that. So I mean, that happens 3 months, quarterly. Like I went for dialysis last week and they told me to bring my medication and they took the list…they going to do some adjustment based upon my lab tests." (Participant # 12, Male)

On the contrary, as seen in the excerpt below, there was not much role of the pharmacist in these participant treatment experiences and decisions. When asked to elaborate on the relationship with the pharmacist, she did not develop further. The participant stated that she receives her medication via mail order.

" Pharmacist great. I don't k now name, I forget name… I use mail order. Mailed to my house. Before they bring they call me to make sure I am home and bring home. Yeah." (Participant # 1, Female)

a) Revealing the diagnosis to a pharmacist

This sub-theme presents the participants' perspective on revealing their HIV status and the ARV medications taken to a pharmacist. When given a scenario "if they have to buy an OTC from any chain pharmacy, if they would go to talk to a pharmacist and ask for guidance and subsequently reveal their positive status and ARV medications," most of them responded affirmatively. As seen in some of the participants' statements, one of the main reasons why they would disclose the status is to avoid any drug-drug interactions.

One participant presents a situation when she went to her local chain pharmacy to ask for the pharmacist's recommendation on OTC. Furthermore, knowing what ARV medications the participant takes offered the opportunity to the pharmacist to consult with her physician and ensured the participant received the appropriate OTC and the potential drug interactions were avoided.

> *"Like, when I was coughing heavily sometime, I went to {Pharmacy Name}, the clinic there. And she even contacted, um- the hospital. To ensure there is no drug interactions and- Mhm, yea."* (Participant # 3, Female)

The same participant also pointed out her opinion about the importance of revealing the diagnosis to the medical professionals. She says:

> *"Everywhere I go. I went to my clinic- clinic, they took the form, put it there. Everywhere I go. Once it's medical place, I let them know."* (Participant # 3, Female)

Similarly, another participant shared her views of the importance of revealing the diagnosis to the pharmacist and also other medical team.

"so- and even I go to dental I have to fill out the form, the medicine I take so yeah, so I have to tell them. Everywhere I go like, they concern about the dental or maybe somebody related, I have to tell them I just write down the medicine that I take so yeah." (Participant # 7, Female)

Another participant reinforces her opinion about the necessity to share her status with a pharmacist. According to her statement, it is essential to receive guidance from a pharmacist because she is immunocompromised, and she might need a different dose.

"Yes, yes. First of all, I'll tell them I'm HIV positive. Yes, because, then we were told, you know what works for someone who is not positive would not work for someone who is positive, because for us we would take maybe a higher dose. Yeah, it would the higher dose so the best thing- the first thing I tell them is I am HIV, so that they know if it is my medication, what- what amount to give me. And of course, pharmacists, they go to school and so they know." (Participant # 10, Female)

On the contrary, one participant became aware of the importance of disclosing not only his HIV status but also the ARV regimen to a pharmacist due to his physician recommendation. According to his statement, he would not have revealed this significant information because he believed it was pointless. In the

quotation below he verbalizes these reasons, explains the conversation with his physician who influenced him to change his mind regarding the diagnosis disclosure, and emphasizes the need to share his diagnosis and ARV medications with the pharmacist in future encounters with the pharmacist.

> *"Mmm. Yes, I actually I just realized that today which usually he did [DOCTOR NAME] just told me I should probably let them know I am taking this medication but I hadn't really thought about it so I never really disclosed that information like I'm taking this kind of medication. Yeah, so I never would disclose it when I would pick up any allergy or fill my medications I never really disclose, I just pick it up. I never thought it would be that impactful. But I guess now as my doctor mentioned it. He did say I could still let them know if I'm prescribed a- if I have a prescribed medication I should probably let them know. But, I felt before like for simple cold medications I never thought it was necessary. And now that I guess now that I know too if I get prescribed- I never had any prescribed medication besides the one I have right now. But yeah, if I ever have in the future I probably do have to start letting them know."* (Participant # 11, Male)

b) Lack of disclosure of the status

This sub-theme presents the participants' statements along with their reasons why they would not disclose their HIV status to a pharmacist.

Before the results of this sub-theme are presented, it is vital to understand the participants' African background regarding the confidentiality rules and trusting of a healthcare professional with their "secret." For example, one of the participants clarified that in Kenya many of the healthcare staff have access to a person's files that contain confidential information such as the HIV diagnosis. According to this participant statement, a healthcare professional could easily open the file and disclose that "secret" to others. She further elaborates:

> *"Yeah, yeah. Those working there who keeps files, they bring the file to the doctor, they open it…they all know. That one is there is Africa. So, we used to get scare of that because already we knew some people who are sick so if you know other people, you know even you are going to be like that."* (Participant # 13, Female)

The information available on the OTC box or ARV medication guide offers sufficient information for a few participants. According to their statements, reading the provided information, it is satisfactory to purchase the OTC, and they would not discuss further their OTC selection with the pharmacist. When asked if they would share any information such as HIV positive status or ARV regimens, the participants in this sub-theme responded negatively.

In the quote below, the participant states that he would not seek the pharmacist's recommendation on an OTC and he would not disclose his status with any medical staff. He reinforced the necessity of hiding his "secret" to all medical professionals.

"No, I will not go to talk to them. Because it did happen to me, it's just only sometimes when I take the {OTC Name} (hiccups). Yea, I just read the prescription, what the information on the box and I go get it and take it at home. uh, ya know, ya, hide it, of course. But I don't go to the counter and talk to it about it, no… No, no, no. I don't mention to them. I don't mention to them because there's no reason to you- you want them to know. Yea. Even some for- I mean, some clinic, like dentist clinic, eye clinic, ya know, when they give you this form to fill out. To fill out what you are, what medication you are taking, I will not put the HIV there, no." (Participant # 4, Male)

Similarly, another participant would not seek the pharmacist's advice because he finds the information on the medication guide informative. This participant also reinforced the lack of disclosure of the HIV status to a pharmacist. Participant # 8 further elaborates:

"I have the prescription, it's already written in that thing. They write, they describe every new thing they try to tell me I have to wait and- just give me the damn thing, I can read, I know about this one." (Participant # 8, Male)

Another participant would not ask the pharmacist's advice because he relies on the physician advice. When asked if he would share his diagnosis with the pharmacist, he responded negatively. He says:

"No. No. What I buy there the {OTC Names}. No. {I don't talk to the pharmacist}. Yeah doctor [NAME] talk about it. Um, about the {OTC Names} I take that sometimes especially in the winter. Yeah, so he {the physician} knows that I'm taking this in the morning sometimes." (Participant # 14, Male)

Another participant mentioned she would not disclose her HIV positive diagnosis with a pharmacist. Furthermore, she would not ask for the pharmacist advice. When asked about the reason, she did not comment.

"No, no, I don't talk to her {the pharmacist}." (Participant # 5, Female)

Discussion

This chapter presents a discussion of the findings of this study. It also includes the limitations. Recommendations for pharmacists and pharmacy educators and for future research are also suggested.

Summary of the Results

The findings of this study illustrated the socio-cultural, personal, religious, and economic experiences of African-born persons living with HIV in Minnesota (PLWHMN), focusing on the medication decision making.

Overall, the lack of awareness of being infected with HIV dominated in all of the participants' narratives. Most of the participants could not pinpoint the circumstances of the infection. Even though all of the participants presented various symptoms of the HIV infection, these characteristics did not identify the possibility of being HIV positive initially.

The “cruel news” that informed the participants of being HIV positive created an “irreversible change” in their lives. All of the narratives presented different emotional states such as denial, depression, wishing “to be dead,” and suicidal thoughts when they received the cruel news of HIV diagnosis. The participants felt impoverished by the positive status and developed their own “coping mechanism” by keeping the diagnosis and the medications secret from the family members, friends, co-workers, and the external world.

All the narratives are distinguished by secrecy despite the fact that decades had passed since he/she were diagnosed with the disease. The secrecy of their diagnosis was observed throughout all the interviews where the participants would refrain from using the word “HIV” and refer it as “this,” “it,” or “the disease.”

The participants faced the dilemma of revealing their “secret” to the loved ones and friends. The fear of not disclosing the “secret” with blood relatives was attributed to the external stigma brought upon themselves and how others would perceive them. Additionally, disclosing their “secret” to the community, the participants felt they would have been judged and discriminated against due to their HIV status. Per the participants’ stories, they went through a painful and emotionally exhausting process of deciding to disclose their “secret” to their loved ones and friends.

Another critical element that emerged from the stories was the fact that participants felt stigmatized at different levels including societal, familial, and individual due to their status. They attributed the external stigma to the existence of misconceptions about HIV transmission in their country of origin. Based on the participants’ experiences, these misconceptions about HIV transmission persisted in their culture even though they now lived in the U.S.

All of the stories were dominated by finding strength and support in God and prayers. From the moment of receiving the “cruel news” of diagnosis God continuously plays an essential role in these participants lives. Participants continue their existence and daily lives due to the Divine power of prayer. The

participants were born and raised in different countries of the African continent. Out of 14 participants, 13 stated they were Christians. Only one participant did not mention his religious affiliation; however, he described how strong beliefs in God were able to provide strength in order to face difficulties.

Participants had faith in the miraculous power of God and believe that He will help scientists to find a cure or vaccine to the disease. Participants also take their ARV medications that are part of their daily routine. Some of the participants attributed their wellbeing not only to God; but also, to medications. On the other hand, one participant did not take medications initially and placed faith in the healing power of the Divinity. After a decade without treatment, the participant-initiated treatment and continued praying for strength.

A key characteristic of the narratives was that the participants take the prescribed medications “to be alive” and also could spend time with family. In addition, a few participants highlighted another vital aspect of taking ARV medications that is not only “to be alive”; but also, to sustain a suppressed viral load and keep the virus undetectable. Six of the participants were diagnosed and started treatment in their country of origin. The rest of the participants received diagnosis and started treatment in the U.S. Regardless of where the participants began treatment; they presented similarities including the experience of side-effects, “pill burden,” symptoms that prompted the physician to start ARV treatment, a larger size of medications and secrecy about taking medications.

Throughout their narratives, the participants highlighted their perspectives on the importance of adhering to the prescribed medications. The recurrence of

the similar purpose “to be alive” and to continue their lives with loved ones was the main reason for the participants of being adherent to ARV medications. Participants want to be adherent to the prescribed regimen; however, issues of insurance coverage might prevent them. Whenever participants experienced any insurance issues, they sought help from a case manager. In order to be adherent to the medication regimen most of the participants use different adherence tools such as an alarm or pill box.

A few of participants’ stories highlighted the fact that they had faith in herbal remedies or in “natural healers” and had used different natural therapies in the past for minor illnesses. A few participants highlighted the usage of various herbal remedies in helping them in the overall wellbeing. On the contrary, a few participants did not believe in herbal remedies and denied the lack of usage.

An important element that emerged through the narratives was that participants’ perceptions of pharmacists’ roles were limited and did not refer to any “patient care” roles. They described the relationship with pharmacists as a “transactional interaction.” Participants received medications from different settings, including retail/ambulatory care pharmacies or mail order. Two participants regularly see a clinical pharmacist with whom they could discuss their ARV regimen.

Discussion of Themes

The results of this study will be discussed within the thematic analysis. Due to the social and cultural context some of the themes were discussed together.

Demographics

The participants were born throughout Africa. The proportion of the narratives in each country sample is four from Ethiopia, four Kenya, two Liberia, and one each from the following countries: Tanzania, Zambia, Togo, and Guinea (See Appendix 5). Although the participants represent Africa as a continent, the prevalence of the HIV diagnosis is different in the designated countries. To illustrate, collectively, six of the participants in the current study were originally from the “high burden” countries, that means that in these countries, there is a high prevalence of HIV ("National AIDS Control Council," 2014). Specifically, Kenya, along with Zambia and Tanzania belongs to the “high burden” countries in Africa due to the high prevalence of HIV ("National AIDS Control Council," 2014). Per a recent report, an estimate of 1.6 million PLWH is in Kenya ("National AIDS Control Council," 2014). The prevalence of the disease in Kenya is 6%, while females are more susceptible to contracting the disease versus males ("National AIDS Control Council," 2014). The four Kenyan participants in this current study were women which highlights more evidence to the prevalence rate in gender distribution.

Per the UNAIDS report, Zambia and Tanzania are another two countries with a high HIV prevalence. For instance, in 2016 approximately 1.1 million people have been diagnosed with HIV and the prevalence of adult HIV is nearly 12% in Zambia ("UNAIDS Report/Zambia," 2016). In the same year, in Tanzania, an estimated 1.5 million PLWH and the prevalence of adult HIV is 5% ("UNAIDS

Report/Tanzania," 2016). To better understand the meanings of high prevalence country for this sample size, the participants from certain countries were more susceptible to contracting the virus. For example, the Zambia participant suspected the infection with the HIV occurred through a contaminated needle. On the contrary, three of the Kenyan females highlighted the fact that they contracted the virus via sexual contact.

On the other hand, four of the participants were of Ethiopian origin; a country were nearly 1.2% of the population is HIV positive ("Analysis: HIV/AIDS is surging in Ethiopia, again," 2017). Although a recent report from Ethiopia noticed an increase in the HIV prevalence, no correlation between the outbreak of the HIV and the participants could be identified because in this sample size the participants have been diagnosed with the disease over a decade ("Analysis: HIV/AIDS is surging in Ethiopia, again," 2017). Furthermore, the SPI did not have control of whom would be enrolled in the current study and cannot be ventured that this representation was intended to match the prevalence in certain countries.

All the participants have been diagnosed one or two decades ago and none of them were recently diagnosed in the last year.

Themes 1, 2, and 3

Symptoms

The lack of awareness of being infected with the virus dominated in all of the participants' stories. Even though the participants might be originally from "high

burden countries" where the HIV infection is more prevalent, none of the participants linked the symptoms with the possibility of being HIV positive.

Although all of the participants mentioned the typical symptoms of the disease, at the behavioral levels the participants had a low HIV risk perception. The literature showed that many HIV positive individuals who had heterosexual intercourse were not aware of being at risk of contracting the disease (Porter, Wall, & Evans, 1993; Samet, Freedberg, Savetsky, Sullivan, & Stein, 2001; Wortley et al., 1995). Additionally, some of the participants mentioned in their narratives the awareness of the HIV prevalence in the country of origin and might have known someone who was HIV positive; however, they were not initially aware of contracting the virus.

Previous studies showed that disclosure of being homosexual in Africa has been controversial and outlawed in various countries (Chitando & van Klinken, 2016). However, in this sample, out of fourteen participants, one person identified himself openly as homosexual, without asking. The data showed that many individuals are afraid of disclosing their sexual orientation in Africa (Chitando & van Klinken, 2016). One plausible explanation in the current study where the participant was open about his sexual orientation is that he lives in the U.S. Furthermore, previous studies conducted globally showed that homosexual men are at a higher risk of contracting HIV (Sanchez et al., 2014), in this current study the participant was not conscious of his positive status before testing.

Diagnosis Impact, Denial, and Secrecy

Being in denial of one's HIV status is a complex phenomenon that has been extensively researched (D. Bangsberg David RMD, MPH Liu Honghu Ph. D., 2011; Moskowitz, Hult, Bussolari, & Acree, 2009). One study conducted in Tanzania explored the association between stigma, revealing of the HIV status, coping mechanisms that included denial or acceptance, and adherence to ARV medications (Lyimo et al., 2014). The study showed that denial is a defensive mechanism that has been attributed to perceived stigma (Lyimo et al., 2014). The denial aspect has been associated negatively with lower adherence to ARV medications (Simoni, Amico, Pearson, & Malow, 2008). However, in our present study, none of the participants stated a poorer adherence to ARV regimen due to the denial process.

The impact of the HIV diagnoses has been described in the literature by different symptoms of depression. As each participant presented his/her emotional story in this study, the HIV diagnosis fostered the presence of depressive symptoms. In the literature, the PLWH receive support from health care professionals and attend social group meetings (Ware, Wyatt, & Tugenberg, 2006). On the contrary, in this current study only one participant mentioned receiving counselling support.

Furthermore, the denial aspect of the diagnosis in our findings resonates with the Ross theoretical framework (Ross, 1969). During this stage, the participants cannot accept the cruel news of the diagnosis. The following sentence is representative to most of the participants regardless of their diagnosis "No, not

me, it cannot be true" (Ross, 1969, p. 51). A previous study applied the E.K. Ross framework to PLWH (Brion, Menke, & Kimball, 2013). The denial stage of the framework showed that the participants had different manifestations during this stage (Brion et al., 2013). For example, some were unwilling to be tested for the disease; despite the fact, they were presenting the characteristic symptoms, while others were not ready to start the ARV treatment (Brion et al., 2013). Our findings corroborated the previous study and showed that the power of denial is ubiquitous.

Theme 3 and 4: Secrecy and Impact of stigma

The stressful aspect of revealing the HIV positive status to others has received a lot of attention in research and has been associated with the fear of discrimination (Dibb, 2018). The external judgement and discrimination perceptions were expressed by this study participants and is mainly the result of stigma associated with HIV. Each participant in this study tended to hide their diagnosis from others as a result of shame. These findings are consistent with the literature that showed many PLHW are not disclosing their status due to the fear of potential discrimination (Stutterheim et al., 2011).

A wealth of research has been conducted on the stigma associated with HIV that continues to be a stigmatizing disease (Ajong et al., 2018; Biru, Lunqvist, Molla, Jerene, & Hallström, 2017). There are limited definitions of the stigma; however, the literature uses terms such as "discrimination," "shame," or "fear" (Sikstrom, 2018, p.177). The stigma terminology is ambiguous and mostly focuses

on the emotions and situations experienced by PLHW (Sikstrom, 2018). To provide an example, some of the participants in the present study used different terminology to describe stigma that brings more evidence to the field.

The stigma experiences have been linked to denial by relatives or friends, shame, and solitude. The participants in this study inferred stigma as shame, and isolation. Link and Phelan proposed a conceptual framework for stigma (Link & Phelan, 2001). According to the proposed framework, stigma has four components and it occurs when these components converge (Link & Phelan, 2001). Per the framework the four components are “labeling”, “negative attributes”, “separation”, and “discrimination” (Link & Phelan, 2001, p.367). The findings of this study resonate with the Link and Phelan conceptual framework. For example, this study showed that the participants were afraid of the consequences of being “labeled” as disease carrier. Once someone knew their HIV positive status a cascade of events would unravel that would result in “discrimination” that is the last component of the framework. Furthermore, this study uncovered a unique finding that is the persistence of stigma in the participants’ community. Even though they live in the U.S. where they feel less stigmatized by the Americans; they still feel stigmatized in their community where the population is predominantly of African heritage.

Lastly, the status loss was described by the framework as “immediate consequence of successful negative labeling and stereotyping is a general downward placement of a person in a status hierarchy” (Link & Phelan, 2001, p. 371). A number of the participants highlighted the fact that many people would be

afraid to be associated with PLWH. For Participant # 11, the status loss was expressed by using the word “ostracized’.

In many of the participants narrative, the stigma at the societal level was attributed to the misconceptions about transmission. To illustrate, the participants mentioned the presence in their country of origin of various misconceptions such as shaking hands, sharing food utensils, or sitting next to PLWH. Despite the fact the participants were coming from different African countries, it was noticed some of the misconceptions were present across the countries. Additionally, in a few narratives, the female participants challenged the misconception that associates the diagnosis of HIV with immorality and promiscuity.

Despite the fact that globally a wealth of research has been conducted on the stigma associated with PLWH, there are limited studies conducted across different countries in Africa. One study conducted in six different African countries compared cross-culturally the content of stigmatizing descriptions with the salient goal to decrease the stigma (Winskell, Hill, & Obyerodhyambo, 2011).

Theme 5: The power of spirituality and prayers

Although previous studies have shown the role of religion played in the lives of PLWH, a novel finding of this study is the role played by a monotheistic religion in all of the participants lives regardless of the country of origin and their faith. Our present study identified a common factor such as the power of prayer and God across seven different African countries.

The influence of God and implicitly Christianity on the PLWH has been highlighted by various studies conducted in Africa (D. J. Smith, 2004; Takyi, 2003). The profound influence of religion could be observed in a few of narratives representing different African countries where the participant reported a change in their sexual behavior not only due to the disease; but also due to their Christian faith they embraced.

Findings from national surveys conducted globally reported which African countries are predominantly Christian or Muslim. According to this report, Christianity predominated in some countries: Zambia (98%), Kenya (85%), Liberia (86%), Ethiopia (63%), Tanzania (61%), and Togo (44%). Guinea (11%) is reported as predominantly Muslim in this report (Pew research center's forum on religion public life, 2012). Within our data, it could be said that all of the participants reported a strong impact of religion and especially Christianity. This could be attributed to their Christian roots origin where religion plays a dominant role in their lives (Pew research center's forum on religion public life, 2012).

References to Christian related activities were present in most of the narratives. While some of the stories demonstrated their engagement in the church activities including the organization of Bible studies, others mentioned the organization of support groups for people with HIV. Prince, Denis, & Van Dijk (2009) have also emphasized the growing impact of the Christian religion on shaping the responses to HIV/AIDS epidemics in various countries in Africa. The authors highlighted the increasing number of religious organizations and their

involvement with fighting HIV in Africa (Prince, Denis, & Van Dijk, 2009). Our data suggest that there are opportunities for PLWH to engage in church-related activities that fight HIV on all the fronts.

Our findings also resonate with the “Bargaining” stage of the framework and the derived model proposed by Ross (Kübler-Ross & Kessler, 2005; Ross, 1969). Participants felt that the prayers and God gave them the strength to face the difficult moments of their lives. For one participant, in particular, her prayers created a bond with God that allowed her not to start ARV treatment for nearly ten years. This participant was actively engaged in her relationship with the Divinity, a finding reflected in the Kubler-Ross model where “most bargains are made with God and are usually kept a secret or mentioned between the lines” (Ross, 1969, p. 95).

Previous research that applied the Ross’ framework on African women with HIV showed that these women appealed to God to live longer or postpone the inevitable by saying “I don’t want to die”(Minnaar & Bodkin, 2009, p. 9). Our findings complement this previous study by showing the participants strongly desire to live by turning their despair into prayers to Divinity regardless where they live.

Theme 6: The significance of taking medications experience

Our data include the unique finding that regardless of the country of origin, the participants' main reason for taking ARV medications was "to be alive" and with the family.

Several of the participants noticed an improvement in their medication regimen since they were started on ARV medications a few decades ago. While some of the participants described a decrease in the number of ARV medications taken daily, others mentioned a reduction in the tablet size or even the side-effects profile. However, the large tablet size or the "pill burden" did not prevent any of the participants from taking the prescribed medications. Earlier research conducted with African-born HIV positive women living in London described the process of taking ARV medications as "invasive, disturbing, and disgusting"(Spiers et al., 2016, p. 2155). These findings are contrary to ours where none of the narratives described the act of taking ARV medications as aggressive or revolting. Furthermore, Spiers *et al*. (2016) suggested further studies to ask the study participants about their "feelings around the physical futures of the tablets" (p.2159). Our current study asked each participant about the physical characteristics of the tablets and most of the participants did not comment. One possible interpretation of these findings was answered by one of the participants who compared her ARV regimen in Africa versus the U.S. According to her statement "the tablets are tiny and easy to swallow in the U.S."

Several of the participants described the process of hiding their ARV medications. A pervious study conducted in London also noted that some of their participants tended to keep their medications secret (Spiers et al., 2016). The

findings of the current study have to be discussed in the social context, where the fear of being stigmatized by the family and colleagues played a major role in hiding the medications. Although a few of the participants were started on ARV medications in the U.S., they would not disclose the medication regimens to the immediate blood relatives, including their children. To avoid HIV stigma in some South African communities the patients might use various practices including hiding the ARV medications or crushing the tablets (E. A. Mills, 2006). Although the participants moved out of their country of origin, a few of the participants still tended to hide their medications. Therefore, our novel findings are suggestive and should be taken into consideration when pharmacists interact with this population.

Participants also talked about their hope that one day the disease will be cured. These narratives resonate with the “Hope” of the Ross framework. In her book, the author describes the hope as “the one thing that usually persists” (Ross, 1969, p. 148). Our study findings show that for some of the interviewed participants, there was a connection between their “hope” of the possibility of a discovering a cure and their desire to live. For Participant # 10, there was a strong linkage between her “hope” to live and the moment when medications would cure the disease. This finding is reflected in the “Hope” chapter that describes how most participants suffering from various terminal illnesses have a wish that a researcher would discover a novel medication that would change their destiny (Ross, 1969).

Theme 7: Barriers and Facilitators in taking ARV medications

Our data showed that the prescribed ARV medications play an important role in the participants lives and all of them wanted to be adherent to medications to continue living their lives. Furthermore, the participants perceived their adherence to the prescribed ARV medications as being very high. Earlier research showed similar results where the participants main reason for having high rates of adherence to ARV medications were to remain healthy (Malcolm, Ng, Rosen, & Stone, 2003). On the contrary, a quantitative study conducted in Minnesota with the African-born population showed a lower adherence rate to ARV medications and the study did not provide insights regarding the reasons for adherence (Akinsete et al., 2007).

A few of participants mentioned other vital reasons for being adherent to ARV medications that was to avoid transmission of the virus to another person. These unique findings are suggestive and show a connection between the participant and the reasons for being adherent.

Most of the interviewed participants mentioned the usage of various adherence tools such as a pill box or phone alarm. These adherence tools not only help them to be adherent to the ARV medications but also to sustain their daily lives with loved ones. Our study findings corroborate prior research indicating that this type of adherence tools provide support and increase adherence to the prescribed medications (Petersen et al., 2007). Furthermore, because this study focuses on the participants' perspectives on the importance of adherence and not the actual rate of adherence to the ARV medications, then the self-presentation bias is not a genuine concern.

A few of the narratives discussed the insurance issues such as being expelled from the coverage or lack of insurance coverage for period of time was the main impediment to adhere to the ARV medications. Our findings bring more evidence to the existing literature that showed that PLWH who had no insurance coverage was associated with an increased risk of not taking ARV medications (Lillie-Blanton et al., 2010). Despite the fact the participants had insurance coverage, a number of them indicated that the co-pay might represent a financial burden.

Theme 8: Accessing to the U.S. healthcare system

Within our data, it could be said that access to the U.S. healthcare system including ARV coverage, physicians, and case managers was a critical aspect mentioned by the participants. Furthermore, the participants are still learning to navigate the U.S. healthcare system.

The previous literature has documented the role played by case managers in the lives of PLWH (Mugavero, Amico, Horn, & Thompson, 2013). The case managers roles could include assistance with referrals for transportation, housing, management of primary medical care (Katz et al., 2001). Furthermore, a study conducted with low social, economic status PLWH living in different urban areas of the U.S. demonstrated that having a case manager was independently associated with enhanced adherence to ARV medications (Kushel et al., 2006). However, this research did not study the potential role of the case manager in helping to solve the insurance issues in PLWH when taking ARV. Consequently,

our novel findings include that the participants rely on the case managers to help them address the insurance issues when picking up ARV medications rather than talking to a pharmacist.

Theme 9: Role of herbal remedies in their treatment

Although the herbal medicine plays a vital role on the African continent (E. Mills, Cooper, Seely, & Kanfer, 2005), our findings divided the participants into two groups. In one group included participants who believed and used some teas and other herbals imported from Africa, while the other group was made of the participants who did not have trust and use them. Several of the narratives discussed their upbringing in an African culture where herbal medicines represent the primary treatment for minor illnesses. A unique finding of this study is that these participants are not using herbal medicines for the treatment of HIV and its related comorbidities. One review highlighted the extensive usage of traditional medicines alone or in combination with ARV medications in different African countries (Orisatoki & Oguntibeju, 2010). This review also drew attention to the potential drug-interactions between the herbal medicine and ARV treatment (Orisatoki & Oguntibeju, 2010). Although some of our study participants acknowledged using some teas and a few of them used herbal extracts they notified their physician and pharmacist to ensure no drug interaction would occur.

Theme 10: Interaction with pharmacists

The interviewed participants described their interaction with the pharmacists as “transactional.” The participants characterized the interaction with the pharmacists positively; however, most of them seemed unaware of the potential role that could be played by the pharmacists in taking ARV medications. Earlier quantitative research showed the role played by pharmacists in adherence to ARV medications in various populations with HIV (Hirsch et al., 2011; Rosenquist, Best, Miller, Gilmer, & Hirsch, 2010). Additionally, the findings of a qualitative study conducted with PLWH and pharmacists in the San Francisco area showed that most of the participants do not think of a pharmacist as part of the adherence team (Jennifer Cocohoba, Megan Comfort, Hamaseh Kianfar, & Mallory O Johnson, 2013). To better serve the PLWH in developing services for HIV one of the recommendations for the pharmacies is to provide adequate workspaces that promote the development of a patient-pharmacist relationship with the main scope of increasing adherence counseling (J. Cocohoba, M. Comfort, H. Kianfar, & M. O. Johnson, 2013). Our unique findings also show that the African-born studied participants did not perceive a personal relationship with the pharmacists. Most of the interviewed participants felt that they were not connected with the pharmacists and whenever they had additional questions regarding their medication regimens, they would contact the physician. For participant # 11, the interaction between pharmacist and the PLWH was described as a “business relationship.” This sense of “business” or “transactional” relationship might come from a lack of understanding of how the U.S. health system works and further knowledge that could be provided by the pharmacist in

counseling and advising them. Another qualitative study conducted with pharmacists from different settings in the Midwest highlighted the fact that pharmacists are not used at their full potential regarding their knowledge and training (Kibicho, Pinkerton, Owczarzak, Mkandawire-Valhmu, & Kako, 2015). This underuse of the pharmacists was also corroborated by our findings that showed most of the participants might not contact a pharmacist for further questions regarding their ARV medications.

Furthermore, during the interview, the participant received a scenario to understand better the reasons why they would or would not disclose their status to a pharmacist. A potential explanation for not revealing the condition to a pharmacist was the lack of trust in the confidentiality of information because of their original roots. A few participants explained and noted the difference between the privacy of medical information in the U.S. versus their country of origin. According to them, in their country of origin, the medical files might be left open, while other people could have access to their medical records. It could result in "gossip." These views were reflected in the findings of a recent qualitative study conducted in South African cities (Duby, Nkosi, Scheibe, Brown, & Bekker, 2018). This study presented situations where the confidentiality of the PLWH was violated in government clinics (Duby et al., 2018).

Conclusions

Participants would prefer to keep their diagnosis and ARV treatment confidential.

The study participants used different mechanisms such as hiding the medications and changing the medication labels to avoid the stigma associated with their HIV status. Most of the participants stated that the stigma persists at different levels including individual, family, and community.

God and, implicitly, the participant's religion helped them get through the difficult moments of their lives.

Being adherent to the ARV treatment helped the participants "to be alive" and share their lives with family and friends.

There were various situations where the participants could not receive their ARV medications due to insurance problems. Whenever they experienced these issues, the participants contacted the case manager who helped them to solve the insurance issues.

The study participants described their relationship with the pharmacist as a "transactional" rather than a caring one. Pharmacists have to take into consideration these aspects when interacting with PLWH.

Limitations

The limitations of this study must be acknowledged.

First, the results from this sample might not reflect social, cultural, and economic factors and believes of taking ARV medications in all African-born PLWH in Minnesota.

Second, the demographics of this sample was limited to gender, country of origin, diagnosis, and initiation of treatment. In order to ensure the confidentiality of the participants, data such as names, ages, addresses, employment, and the number of years spent in the U.S. were not collected.

Third, this study did not use any medical records to validate the reported diagnosis, the ARV medications used, and the self-reported adherence to treatment. Recall bias could have further biased the results.

Fourth, all of the participants in this study reported themselves as adherent to the ARV medications. The reported high perceived adherence rate in this study could not be checked against data claims or medical records. Nevertheless, even within this sample, all of the participants had a form of insurance at the time of the interview. Finding non-adherent or non-insured participants was challenging because recruitment occurred via fliers through pharmacies, clinics, and the HIV center. Consequently, this sample might not be representative of the full spectrum of the African-born PLWH in Minnesota.

Fifth, the participants in this study represented seven countries from Africa where their medication experiences may vary within their own country and culture. The participants discussed mainly their ARV medications and did not refer to other medications taken for various comorbidities. Although some of the participants

took other medications due to the side effects of the ARV regimen, none of them provided details about these medications.

Sixth, although data about their level of education was not collected, most of the participants mentioned during the interview that they have a higher level of education in the country of their origin. Subsequently, most of them had English as the first language.

Aims and Further Research

Although these limitations, the unique findings of this study addressed the aims and provided a better understanding of the social, cultural, and economic factors of PLWH when taking ARV medications.

For aim 1: The main reason why the participants take ARV medications was “to be alive” so they could spend time with their loved ones. Another reason was to have a suppressed viral load that will not transmit the disease to another person. They showed “hope” that the scientists will discover a cure for the disease. The cultural background influenced their ARV medication experiences. Most of the participants were started on ARV medications when the disease was a “death sentence.” Some of the participants used to hide their medications from families, friends, and colleagues. Depending on the circumstances, a number of the participants still keep their diagnosis and medications as a “secret.”

For aim 2: Even though the participants live in the U.S., they perceived the stigma associated with HIV status persisting in their culture at, including individual, family, and societal levels. Most of the participants highlighted that they feel less

stigmatized by the Americans; however, they feel still stigmatized in their community where the population is predominantly of African heritage. In order to avoid any stigmatization in their society, most of the participants would not disclose their HIV positive status to their circle of friends who are also originally from Africa. The presence of various misconceptions about the transmission of the disease persists in their culture.

The participants were initially from seven different African countries, and all of them had strong beliefs in God. All of them believed in a monotheistic God who played an essential role in their daily lives. The Divinity and prayer offered them strength to face difficult moments in their lives.

Some of the participants had faith in the herbal remedies imported from Africa. If they used some teas or other herbal remedies, they would have informed their physician.

For aim 3: The participant used various adherence strategies to be adherent to the ARV medications. One of the main barriers was insurance issues that restricted their adherence to ARV medications management. The participants are still learning how to navigate the unfamiliar U.S. healthcare system including insurance issues that prevented them from taking ARV. Whenever participants experienced any insurance issues, they sought help from a case manager and not a pharmacist.

For aim 4: The participants received medications from different settings, including retail/ambulatory care or mail order pharmacies, and expressed a

“logistical interaction” with the pharmacist. These participants seemed unaware of the pharmacists’ roles in their medication management. Whenever they have questions about their ARV regimen, they sought the physician’s advice. When presented with a scenario if they would disclose their disease status to a pharmacist, the responses were divided into two groups. One group would disclose their status and ARV medications to a pharmacist, while the other group would not disclose the information.

Recommendations for Pharmacists and Pharmacy Educators

This study showed that these participants seemed unaware of the possible roles that pharmacists could play in their ARV medication management. For example, whenever they experienced any insurance issues, they would contact a case manager. Pharmacists have the opportunity to take more proactive roles to solve these issues. This would avoid any delays and would ensure the participants are adherent to the prescribed medications.

When interacting with African-born PLWH, the pharmacists have to be mindful of the social and cultural background by keeping in mind these participants are afraid of disclosing their HIV status and implicitly ARV medications because of the confidentiality reasons. The participants are coming from various African countries where confidentiality laws are different and might not be as strictly enforced as in the U.S. Therefore, re-assuring the information about their disease state and medications is confidential would allow the pharmacists to develop a relationship with the participants. In order to develop a more “caring” relationship,

the pharmacists could use a private space where they could counsel and address the participant's needs.

Lastly, the pharmacists could bring more awareness about their roles in medication management and a source of health-care information. This awareness could be achieved by collaborating with physicians and other healthcare providers who could recommend talking to a pharmacist. Additionally, reinforcing the confidentiality of information when counseling not only prescriptions, but also on OTC, or pointing out they could call the pharmacist whenever they have questions.

Furthermore, pharmacy educators might use some of the findings uncovered in this study when they teach students. For example, incorporating some socio-cultural aspects when creating the pharmacotherapy cases, it would prepare the students to understand better the various populations they would encounter in their future practice. Encouraging pharmacy students to develop more interprofessional healthcare fairs in the African-born community would be beneficial to the patient, student, pharmacist, and educator. The healthcare fair would be an excellent opportunity to bring awareness of the pharmacists' roles in the community.

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Appendix 1: IRB Approved Recruitment Flier

This research study is being conducted by the University of Minnesota

VOLUNTEERS NEEDED FOR RESEARCH ON EXPERIENCES OF HIV MEDICATIONS

Who can participate?

Persons born in Africa, who are living with HIV, currently take HIV medications, and are above 18 years old

What will I have to do?

You will participate in 30 minutes-2 hours one-on-one interview

What will I get out of it?

You will receive a $50 gift card

If you are interested contact Alina at

224-436-0080

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Appendix 2: IRB Approved Consent Form

CONSENT FORM

Understanding Barriers and Facilitators to HIV medications in African-Born Minnesotans, Protocol # 00001597

Researcher: Jon C. Schommer

Student: Alina Cernasev

Supported By: This research is supported by University of Minnesota.

Why am I being asked to take part in this research study?

We are asking you to take part in this research study because you are born in Africa, live in Minnesota, are HIV positive, and are taking medications for HIV.

What should I know about a research study?

Someone will explain this research study to you.

Whether or not you take part is up to you.

You can choose not to take part.

You can agree to take part and later change your mind.

Your decision will not be held against you.

You can ask all the questions you want before you decide.

Who can I talk to?

For questions about research appointments, the research study, research results, or other concerns, call the study team at:

Researcher Name: Alina Cernasev Researcher Affiliation: University of Minnesota Phone Number: 224-436-0080 Email Address: cerna004@umn.edu	Study Staff (if applicable): Phone Number: Email Address:

This research has been reviewed and approved by an Institutional Review Board (IRB) within the Human Research Protections Program (HRPP). To share feedback privately with the HRPP about your research experience, call the

Research Participants' Advocate Line at 612-625-1650 or go to https://research.umn.edu/units/hrpp/research-participants/questions-concerns. You are encouraged to contact the HRPP if:

Your questions, concerns, or complaints are not being answered by the research team.

You cannot reach the research team.
You want to talk to someone besides the research team.
You have questions about your rights as a research participant.
You want to get information or provide input about this research.

Why is this research being done?

The purpose of this study is to look at the social, cultural, personal beliefs and economic factors that might influence your decision to take medications for HIV. I also want to understand the patients' perception of clinical pharmacists' roles in advising you to take HIV medications. There are little benefits for you, but the results will help us to gain a better understanding of this population factors that might influence them when taking HIV medications.

How long will the research last?

We expect that you will be in this research study for 1 hour.

How many people will be studied?

We expect about 15 people here will be in this research study.

What happens if I say "Yes, I want to be in this research"?

If you agree to be in this study, I will interview you for 30 minutes up to 1 hour in a place and time convenient to you. I will ask you questions about your experiences of taking HIV medications. With your permission, the interview will be audio taped. If you do not wish to be audio taped, then your decision will be respected. I will never ask your name, so I will call you "Participant # "and you will never be associated with the obtained information.

What happens if I say "Yes", but I change my mind later?

You can leave the research at any time and it will not be held against you.

What happens if I do not want to be in this research?

You can leave the research at any time and it will not be held against you.

Will I be compensated for my participation?

If you agree to take part in this research study, we will pay you $50 Target gift card for your time and effort.

Appendix 3: IRB Approved Semi-structured Interview

Interview Script and Questions for Patients

Disclaimer: Okay, so we'll get started. Thank you so much for coming. I have a list of questions and what we're going to be looking at is really what your experience on taking HIV medications and what you think is the role of pharmacist. There are no right or wrong answers. Please feel free not to answer question. It's really about your medication experience, and you're the only one who knows your medication experience.

Before we start with the questions, I will address you with participant # and if it possible could you tell me which country in Africa you were born and your age.

1) Can you tell me your story of when you were first diagnosed with HIV?
   [Let the narrative go on as long as possible, with only simple prompting by asking, 'What happened then? And then?']
   - If they talk about their culture: Can you tell me about your culture and the perception of HIV.

2) Please walk me through your day and talk to me about your prescription medications.
   Prompts: if the patient did not talk about:
   - How many times per day do you take them?
   - How often do they take them?
   - Do you take them with food? Water?
   - Do you feel the medications are working well?
   - What do you dislike about them? For example, size, color, taste?
3) Can you tell me how you remember to take your medications?
   - Do you use pill box? Phone alarm?

4) Can you tell me the story of when you forgot to take medications and what do you do when you forgot? Anything you could remember about the experience.

5) Can you talk to me about your culture and if it is it OK to talk about HIV? Taking HIV medications?

6) Can you tell me about your spiritual life, faith or religious practice that helped you go through this difficult period? [Let the narrative go on as long as possible, with only simple prompting by asking, 'What happened then? And then?']

7) Can you tell me how you pay for your medications?

8) Can you tell me what other things help you to improve your health? Hint: do you use herbals, remedies?
   Prompts: if the patient talks about the usage of herbals, then these questions might be pertinent:
   - What stores are you shopping at?
   - What do you shop there?
   - For example, food, herbals, remedies?

9) Can you tell me what it was like talking to your pharmacist about your HIV medications? Scenario: if you have to purchase an OTC (for example….) from a retail store such as …would you go to ask the pharmacist to receive guidance? Would you disclose your disease and medications to a pharmacist? Why or why not?

10) Is there anything else you want to tell me about your HIV medications?

Appendix 4: IRB Approval

EXEMPTION DETERMINATION

December 5, 2017

Jon Schommer
612-626-9915
schom010@umn.edu

Dear Jon Schommer:

On 12/5/2017, the IRB reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	Understanding Barriers and Facilitators to HIV medications in African-Born Minnesotans
Investigator:	Jon Schommer
IRB ID:	STUDY00001597
Sponsored Funding:	None
Grant ID/Con Number:	None
Internal UMN Funding:	None
Fund Management Outside University:	None
IND, IDE, or HDE:	None
Documents Reviewed with this Submission:	• Modified CONSENT FORM- Alina Cernasev.docx, Category: Consent Form; • Interview Script and Questions for Patients.docx, Category: Other; • Alina Cernasev-Flier for recruitment.docx, Category: Recruitment Materials; • HRP-580 - Alina Cernasev-Updated Version.docx, Category: IRB Protocol

The IRB determined that this study meets the criteria for exemption from IRB review. To arrive at this determination, the IRB used “WORKSHEET: Exemption (HRP-312).” If you have any questions about this determination, please review that Worksheet in the HRPP Toolkit Library and contact the IRB office if needed.

This study met the following category(ies) for exemption:

- (2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that Human Subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the Human Subjects responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects financial standing, employability, or reputation.

Ongoing IRB review and approval for this study is not required; however, this determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit a Modification to the IRB for a determination.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the HRPP Toolkit Library on the IRB website.

For grant certification purposes, you will need these dates and the Assurance of Compliance number which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003).

Sincerely,

Clinton Dietrich, MA, CIP

IRB Analyst

We value feedback from the research community and would like to hear about your experience. The link below will take you to a brief survey that will take a minute or two to complete. The questions are basic, but your responses will help us better understand what we are doing well and areas that may require improvement. Thank you in advance for completing the survey.

Even if you have provided feedback in the past, we want and welcome your evaluation. https://umn.qualtrics.com/SE/?SID=SV_5BiYrqPNMJRQSBn

Appendix 5: Demographic of the Participants

Table 1: Demographics of the participants

Participant	Gender	Marital Status	Country of origin	Country/ Year of Diagnosis	Country where treatment started
# 1	Female	N/A	Tanzania	U.S. N/A	U.S.
# 2	Female	Widow	Zambia	U.S. 1996-1997	U.S.
# 3	Female	Divorced	Liberia	U.S. 2008	U.S.
# 4	Male	Married	Ethiopia	Ethiopia 2006	Ethiopia
# 5	Female	Married	Guinea	U.S. N/A	U.S.
# 6	Male	Married	Ethiopia	Ethiopia 2004	Ethiopia
# 7	Female	Divorced	Kenya	Kenya 1994	Kenya
# 8	Male	Single	Ethiopia	U.S. 2013	U.S.
# 9	Female	Married	Kenya	Kenya 2002	Kenya
# 10	Female	Divorced	Kenya	Kenya 2005	Kenya
# 11	Male	Single	Ethiopia	U.S. 2005	U.S.
#12	Male	Single	Liberia	U.S. 2009	U.S.
# 13	Female	Divorced	Kenya	Kenya N/A	Kenya
# 14	Male	Married	Togo	U.S. 2001	U.S.